Iowa Comprehensive HIV Plan

2012-2015

The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socioeconomic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.

Vision

of the National HIV/AIDS Strategy, July 2010

Table of Contents

Plan Development Committee Members

Kenneth Allen
Nichole Baker-Jones
Twyla Berry
Colleen Bornmueller
Erica Carrick
Cheryl Carter
John Chamberlain
Tasmania Clayburn
Kristine Davis
Jordan Delmundo
Janelle Durlin
Linnea Fletcher
Kevin Gabbert
Julie Gilbert
Greg Gross
Holly Hanson
Jerry Harms
Patresa Hartman
Tami Haught
Mark Hillenbrand
Becky Johnson
Betty E. Johnson
Virginia Jorden-Wackens
Tim Kelly
Tim Kiss
Tricia Kroll
Jodie Liebe
Randy Mayer
Elizabeth McChesney
Courtney McCrellias
Jeffery Meier
Sandee Millage
Jeffrey Moore
Jeff Mullen
Brian O'Gary
Linda Peerson
Darla Peterson
Kurt Pierick
Beth Riechers
Nick Rhoades
Heather Roby
Shane Scharer
Jordan Selha
Roma Taylor
Pam Terrill
Michele Tilotta
Virginia Tonelli
Rhea Van Brocklin
Amy Wadlington
George Walton
Kathy Weiss
Denise Wheeler
Shannon Wood
Patricia Young
David Yurdin

Reviewers

Scott Clair
Kaitlin Emrich
Amber Lewis
Nate Monson
Paula Paider Licht
Sara Peterson
Breanne Ward
Elizabeth Wilson

thank you.

Common Acronyms Found in This Document

ACA	Affordable Care Act (also called the Patient Protection and Affordable Care Act)
ADAP	AIDS Drug Assistance Program
AETC	AIDS Education and Training Center
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CARE Act	Ryan White Comprehensive AIDS Resource Emergency Act/Ryan White HIV/AIDS Treatment Extension Act
CASA	Care Assessment and Strategic Access Committee
CBA	Capacity Building Assistance
CBO	Community Based Organization
CDC	Centers for Disease Control and Prevention
CHAIN	Community HIV/Hepatitis Advocates in Iowa Network
CLEAR	Choosing Life: Empowerment, Action, Results
CNA	Consumer Needs Assessment
CTR	Counseling, Testing, and Referral
CRCS	Comprehensive Risk Counseling and Services
CQI	Continuous Quality Improvement
DPS	Disease Prevention Specialist (also called Disease Intervention Specialist)
DQA	Data Quality Assurance
EBIs	Effective Behavioral Interventions
eHARS	Enhanced HIV/AIDS Reporting System
EIIHA	Early Identification of Individuals with HIV/AIDS
EIS	Early Intervention Services
EPIC	Epidemiological Profile and Information Committee
FOA	Funding Opportunity Announcement
FP	Family Planning
GBT	Gay/Bisexual/Transgender (men's community)
GLBT	Gay/Lesbian/Bisexual/Transgender
HAART	Highly Active Antiretroviral Therapy

HCV	Hepatitis C Virus
HE/RR	Health Education/Risk Reduction
HHS	Health and Human Services (Department of)
HIPP	Health Insurance Premium Program
HIV	Human Immunodeficiency Virus
HOPWA	Housing Opportunities for Persons with AIDS
HPTN	HIV Prevention Trials Network
HRSA	Health Resources and Services Administration
HUD	Housing and Urban Development
IDE	Iowa Department of Education
IDHS	Iowa Department of Human Services
IDOC	Iowa Department of Corrections
IDPH	Iowa Department of Public Health
IDU	Injecting Drug User
IFA	Iowa Finance Authority
LGBT	Lesbian/Gay/Bisexual/Transgender
MATEC	Midwest AIDS Training and Education Center-Iowa Site
MEPD	Medicaid for Employed People with Disabilities
M&E	Monitoring and Evaluation
MMWR	Morbidity Mortality Weekly Report
MOA	Memorandum of Agreement
MOB	Membership Orientation and Bylaws Committee
MSM	Men who have Sex with Men
MSM/IDU	Men who have Sex with Men and who inject drugs
NARC	Needs Assessment/Community Resources Committee
NACHC	National Association of Community Health Centers
NASTAD	National Alliance of State and Territorial AIDS Directors
NCSD	National Coalition of STD Directors
NIR	No Reported or Identified Risk
PCIP	Pre-existing Condition Insurance Plan
PIR	Parity, Inclusion, and Representation
PITCH	Positive Iowans Taking Charge
PLWHA	People Living With HIV/AIDS

PPACA	Patient Protection and Affordable Care Act
PR	Public Relations Committee
PS	Partner Services
PSA	Public Service Announcement
QA	Quality Assurance
QM	Quality Management
QUAC	Quality Assurance/Case Management Standards Committee
REHD	Racial and Ethnic Health Disparities Committee
RFP	Request for Proposal
RWCA	Ryan White Care Act
SAMHSA	Substance Abuse and Mental Health Services Administration
SCSN	Statewide Coordinated Statement of Need
SDH	Social Determinants of Health
SiHLE	Sisters, Informing, Healing, Living, Empowering
SPICE	Strategies for Prevention Interventions and Community Endeavors Committee
SSDI	Social Security Disability Insurance
SSI	Social Security Income
STD	Sexually Transmitted Disease(s)
TA	Technical Assistance
TASC	Taking a Stand Committee
TasP	Treatment as Prevention
TB	Tuberculosis

Introduction and Background

The *2012-2015 Comprehensive HIV Plan* serves as a statewide guide to responsive, effective, and efficient HIV service delivery in Iowa. Goals and strategies included in the strategic plan are designed to meet the specific needs of Iowans who are at high-risk for HIV infection, who are members of populations disproportionately impacted by HIV, and/or who are living with HIV/AIDS.

In accordance with direction from the Iowa Department of Public Health's primary federal funding agencies for HIV-related programs, the U.S. Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), this comprehensive plan has been developed to improve the effectiveness of the state's HIV prevention and care programs by strengthening the scientific basis, relevance, and focus of prevention and care strategies. This goal was accomplished in collaboration with an ad hoc Plan Development Committee.

The plan is structured to answer four questions that parallel those asked during Iowa's comprehensive planning process:

Section 1- What is the state of HIV prevention and care in Iowa?
Section one presents the current "state of the state" summary. A description of Iowa's landscape lays the foundation for a better understanding of the state's HIV epidemic. The current continuum of prevention and care is presented with updates about recent progress in implementing previous goals and objectives.

Section 2- Where are we now and where would we rather be?
Section two describes the current state of Iowa's HIV/AIDS epidemic and contrasts this picture with a preferred future in which the impact of HIV is reduced by improved prevention and care efforts. Recent assessments, epidemiological data, and evaluations are discussed telling the story of prevention and care successes, barriers, gaps, and trends in Iowa. These materials provided background to the planning process and help inform the reader about priorities for future efforts in Iowa.

Section 3- How will we get there?
Section three defines the efforts needed to achieve the future described above. Strategic activities developed by the Plan Development Committee are indicated and will be used to direct HIV efforts throughout the state.

The resulting document provides a blueprint for the delivery and prioritization of prevention, care, and HIV-related health disparities in Iowa. The completed Comprehensive Plan will be used by the Iowa Department of Public Health (IDPH) to prioritize the utilization of federal funds for HIV prevention and care, including the moneys it awards to community-based organizations and local health departments. IDPH expects funded activities to help the state move in the direction indicated in section two of the plan using the activities described in section three.

Since the last *Comprehensive HIV Plan* was developed in Iowa, an important development occurred. Early in his administration President Obama asked the Office of National AIDS Policy to develop a national HIV/AIDS strategy for the country. The resulting National HIV/AIDS Strategy (NHAS) was unveiled in June 2010. Included in the strategy's release was an expectation of states to develop their own implementation plans to contribute to the goals of the NHAS.

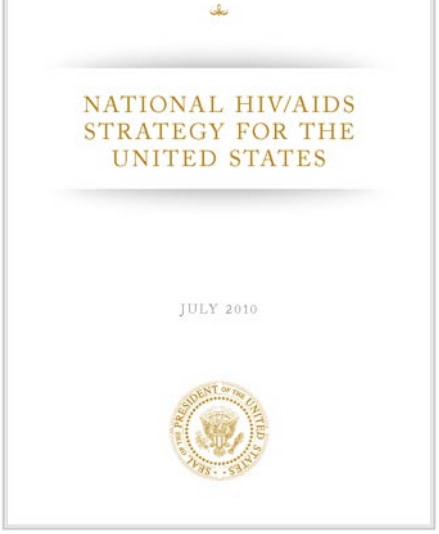
Goals of the National HIV/AIDS Strategy

1. Reducing New HIV Infections;

2. Increasing Access to Care and Improving Health Outcomes for People Living with HIV;

3. Reducing HIV-Related Disparities and Health Inequities; and

4. Achieving a More Coordinated National Response to the HIV Epidemic.



The goals of the NHAS have influenced the way in which prevention and care planning integration has and will continue to evolve in Iowa.

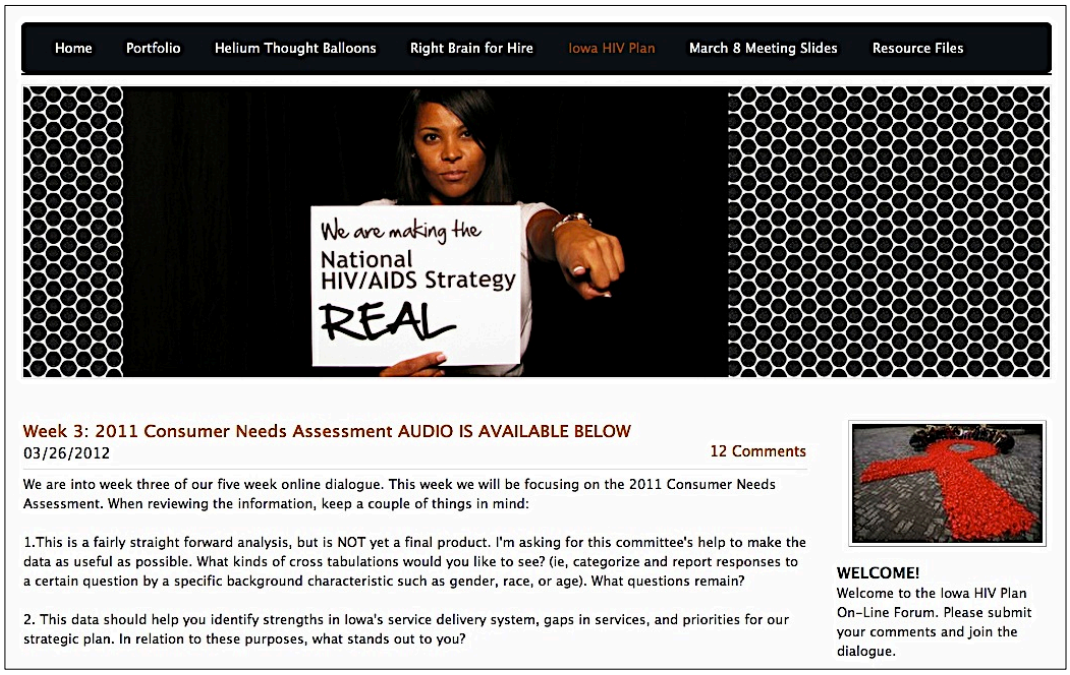
Plan Development Process

Then- IDPH has a long history of implementing planning processes that incorporate the views and perspectives of providers of HIV prevention and care services and of people infected and affected by HIV, for whom the programs are intended. IDPH initiated an HIV prevention community planning process in 1994. The Iowa HIV Community Planning Group (CPG) was formed during this time and was composed of people who brought diverse expertise and life experiences to the planning process. In 2001, the CPG began to integrate care planning into the process. In 2005, the group expanded its statewide care planning component to increase consistency in delivery of services across the state. Although Iowa has had a combined prevention and care planning group for many years, it had continued to have two separate plan development processes; one to meet HRSA's requirements, including the Statewide Coordinated Statement of Need (SCSN), and another to develop the statewide HIV prevention plan, as required by CDC. The results of these processes were then combined into one Comprehensive HIV Plan for the state.

Now- During the development of the current process it was decided that the two planning processes would be fully integrated to reflect and build upon the integrated approaches to HIV prevention and care that are effective in Iowa. At the same time, a planning process was designed to align the plan with the National HIV/AIDS Strategy, which already was having serious impacts on the way in which prevention and care services were to be delivered in the state.

In February, 2012, IDPH initiated a broader engagement process that included, but was not limited to, members of the CPG. The goal was to formulate a collective vision that would assist IDPH in contributing to the goals of the NHAS through coordination and collaboration with Iowa stakeholders. An ad hoc Plan Development Committee was formed comprised of all CPG members as well as key stakeholders that included Ryan White Parts B, C, and F (Midwest Training and Education Center-Iowa site), prevention providers, consumers of HIV care and prevention services, and collaborators from the fields of substance abuse, mental health, housing (HOPWA), corrections, STD, hepatitis, Medicaid, education, family planning, community health centers, and the Iowa Primary Care Association. This group was charged with the development of Iowa's Comprehensive HIV Plan.

The group process was divided into three components. First, the group spent six weeks reviewing epidemiological data, state and national trends, program updates, survey results, personal experiences, and general information about HIV in Iowa. The purpose of this first stage of the planning process was to ensure all participants had a shared knowledge of Iowa's HIV epidemic. Information was shared through webinars, conference calls, and one in-person meeting held in March. In addition, a website portal was developed providing access to PowerPoint presentations, research articles, webinars, and other information. This phase of the process continued after the March meeting with six weekly topics posed for virtual discussion. A blog section of the website was used to post information and pose questions to the group for discussion.



Topics of the Virtual Dialogues

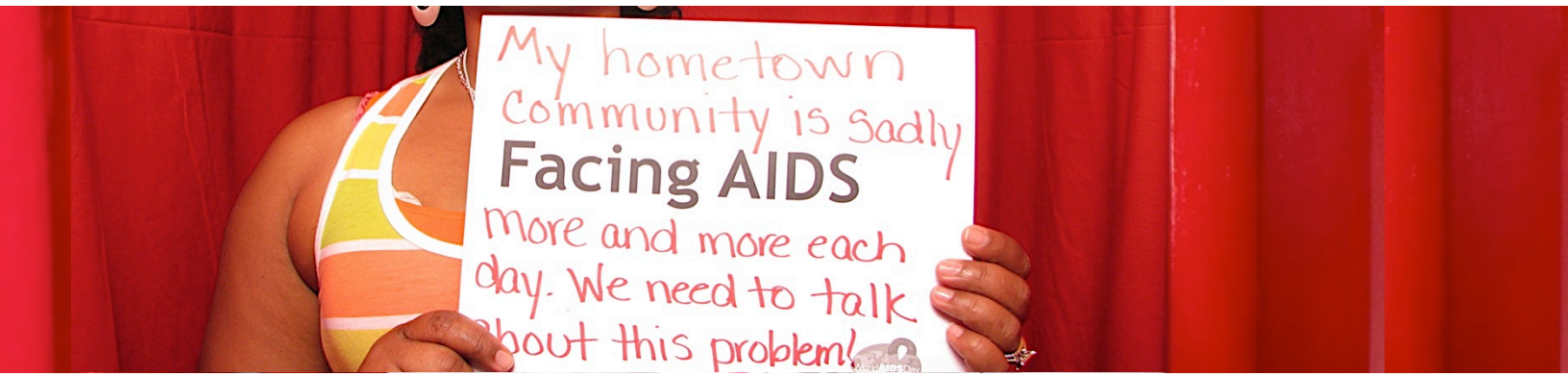
- **Meeting Follow-up:** Opportunity to ask questions and make comments after having had time to reflect on the meeting content.
- **2009 Statewide Coordinated Statement of Need:** The group was asked to review the prior SCSN and then discuss met and unmet needs.
- **2009 Ryan White Strategic Plan:** Comments were solicited to evaluate accomplishments, discuss barriers encountered, and identify remaining areas of focus.
- **2011 Consumer Needs Assessment:** Survey results were presented during a webinar and then posted on the website for members to identify strengths and gaps in services, as well as future priorities.
- **Evaluation of the Prevention Implementation Plan:** The committee was encouraged to review updates to the implementation plan showing completed goals. Strengths, barriers, and remaining focus areas were discussed. Survey data from the Consumer Needs Assessment, Provider Services Survey (for providers of services to men who have sex with men), and Behavioral Survey of Men Who Have Sex With Men was also shared and discussed via conference call.
- **Unmet Need:** Finally, the group reviewed the current statement of unmet need in Iowa and also learned about a pilot re-engagement in care initiative that was in the planning stages.

Information considered during this part of the process can be found in the first two sections of this plan.

Two months were spent focusing on Iowa's epidemic and answering the question, "Where are we now?" Next, a second face-to-face meeting was held over the course of two days to prioritize goals and objectives to answer the question "where do we want to be?" The committee was divided into small groups to focus on specific priority areas. The groups included prevention, case finding, and linkage; engagement and retention in care; re-engagement for individuals who are out of care; HIV-related stigma; and continuous quality improvement. Using information presented from the previous two months, groups were first asked to create mind maps (see figure to right), which were visual representations of inputs, barriers, and pathways needed to achieve desired outcomes in each of the focus areas.

During the final phase of planning, the small groups were asked to develop strategic activities to address the question, How will we get there?" All of this information was then synthesized into the strategic plan found in the final section of this document. This plan was posted and made available for input from the Plan Development Committee, and submitted to the Iowa HIV Community Planning Group for final approval.

Mind maps were created to help visualize key focus areas and begin to formulate goals and objectives to address gaps, overcome barriers, and maximize strengths.



SECTION 1. STATE OF THE STATE

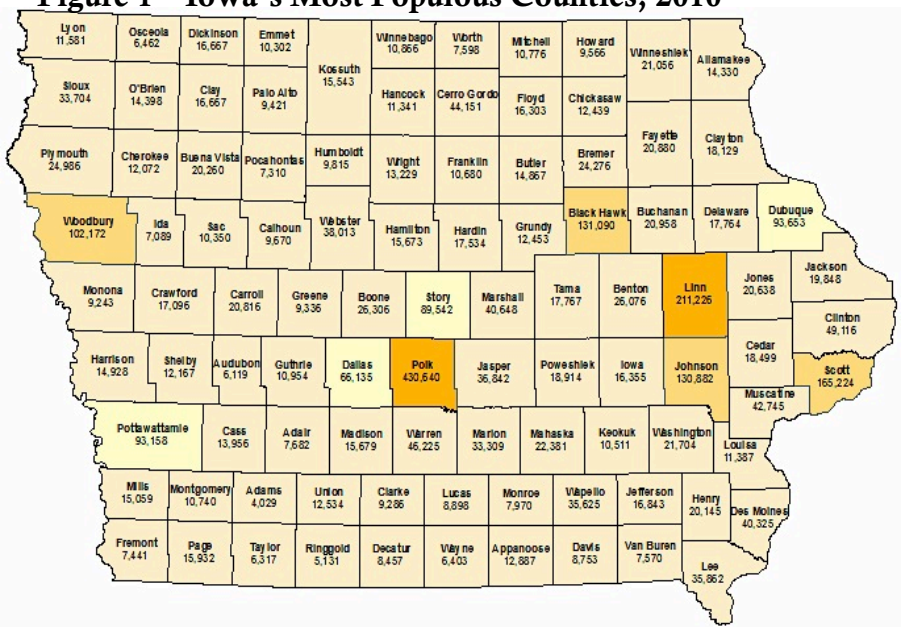
The upcoming section focuses on the current "state of the state," beginning with a description of Iowa's general population characteristics. The state's HIV epidemic is also described through surveillance data describing the people who have been diagnosed with HIV and AIDS in the state. Finally, the continuum of prevention and care is described along with updates about the status of programming and services.

Iowa's Population

Iowa is an agricultural state, with a land area of 55,869 square miles. Iowa comprises 99 counties (Figure 1) with an estimated 2010 population of 3,046,355 persons. The state ranks thirtieth in the nation in population. Five counties (Dallas, Dubuque, Pottawattamie, Story and Woodbury) have between 50,000 and 120,000 people, and five counties (Black Hawk, Linn, Johnson, Polk and Scott) have more than 120,000 people (Figure 1). In 2000, Clinton County was the tenth most populous county, with just over 50,000 persons. Since then, the population is estimated to have declined to fewer than 50,000. In 2005, Dallas County surpassed Clinton County to become the tenth most populous county in the state.

Iowa's population has shifted over the past ten years from rural to urban centers with the most significant growth occurring in and around the capital of Des Moines (Polk County) and in the Interstate-380 corridor between Iowa City and Cedar Rapids (Johnson and Linn counties, respectively). In 2008, the state population estimate exceeded three million for the first time.

Figure 1 Iowa's Most Populous Counties, 2010



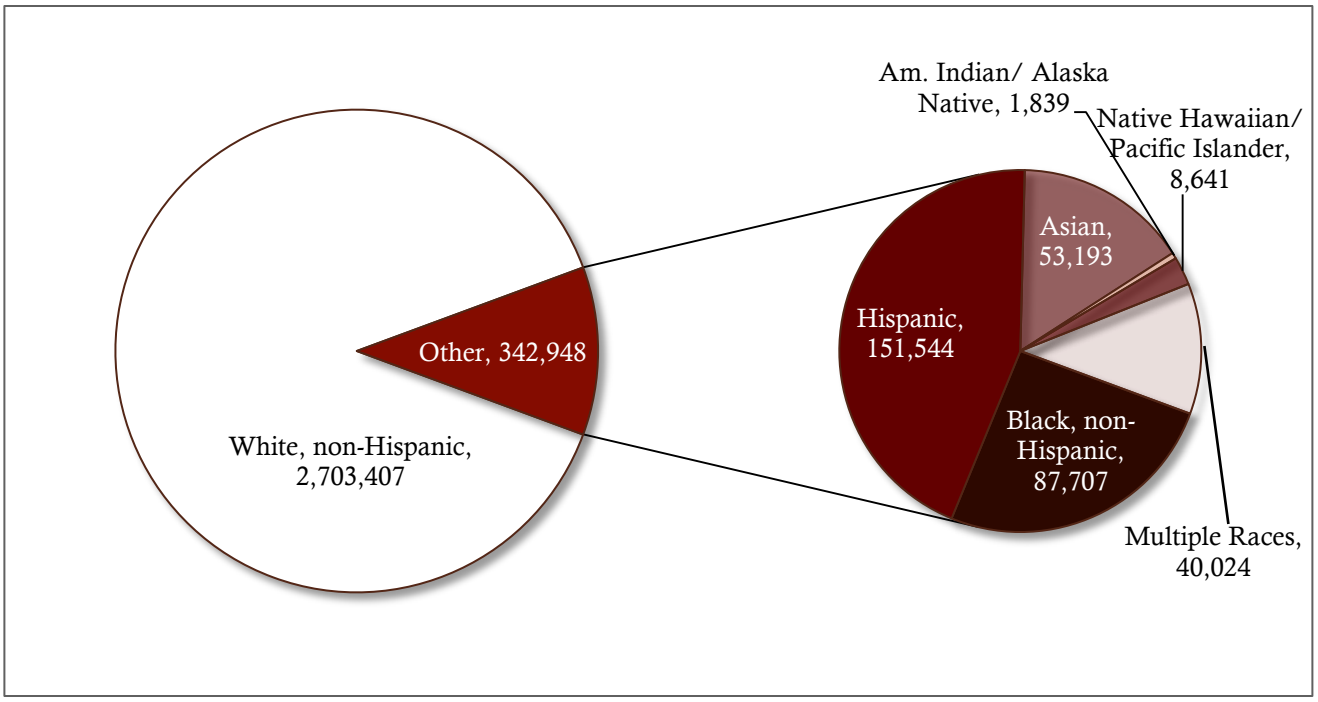
Racial and Ethnic Distribution

About 89% of Iowa's population is white and non-Hispanic (Figure 2; Table 1). Hispanic residents have become the largest minority population in Iowa and are now estimated to account for approximately 5% of the population. At the time of the 2010 census estimate, more than one-half (54%) of the state's Hispanic residents lived in Pottawattamie, Johnson, Marshall, Muscatine, Polk, Scott, and Woodbury counties.

The next largest minority group is black, non-Hispanic residents, accounting for an estimated 2.5% of the population and reflecting a slight increase from 2.1% in the 2000 census. Black Hawk, Johnson, Linn, Polk, and Scott counties account for nearly three-fourths of the state's total black, non-Hispanic residents. The number of black residents is projected to double by the year 2040.

Figure 2 Population by Race and Ethnicity

Iowa Estimated Population, 2010



Iowa's Asian population increased from 1.3% in 2000 to 1.7% in 2010. More than half (52%) of the state's Asian population lived in Johnson, Polk, or Story counties in 2010. Johnson and Story house the two largest state universities. American Indians constitute the smallest ethnic population in Iowa, making up 0.4% of the total population. In 2011, the largest numbers of this ethnic group lived in Tama, Polk, and Woodbury counties.

Net *migration* (i.e., net movement of foreign and/or domestic persons into or out of Iowa) was a negative 6,317 persons from 2000 to 2010. In other words, more people moved out of Iowa than moved into the state. Migration into Iowa was largely the result of emigration from other countries. From 2000 to 2010, 38,692 foreign immigrants entered the state. At the same time, 45,009 persons left the state to immigrate domestically. This means that the increasing diversity in Iowa's

population is mainly the result of persons moving into Iowa from other countries rather than an influx of minorities from elsewhere in the U.S. (US Census Bureau, 2011).

Table 1
Iowa's Population by Race, Ethnicity, and Gender
2010

Race and Ethnicity	Females		Males		Total	
	#	(%)	#	(%)	#	(%)
White, non-Hispanic	1,373,062	88	1,330,345	89	2,703,407	89
Black, non-Hispanic	41,342	3	46,365	3	87,707	3
Hispanic	71,553	5	79,991	5	151,544	5
Asian	26,792	2	26,401	2	53,193	2
Am. Indian/ Alaska Native	897	--	942	--	1,839	--
Native Hawaiian/ Pacific Islander	4,393	--	4,248	--	8,641	--
Multiple Races	19,997	1	20,027	1	40,024	1
Total	**1,538,036**		**1,508,319**		**3,046,355**	

Source: U.S. Census Bureau

Age Distribution

Iowa's population is aging. The median age of the population is 38.1 years, up from 34.1 years in 1990. By 2030, the median age is expected to climb to 39.9 years. With 15% of its population 65 years or older, Iowa ranks 4th in the nation in the percentage of elderly persons residing in the state. The percentage of the population over age 65 is expected to increase to 22.4% by 2030 (U.S. Census Bureau). The percentage of youths (under the age of 18) is expected to decrease from 25.1% in 2000 to 22% by 2030. The 2010 population by gender and selected age groupings are displayed in Table 2.

Table 2
Iowa's Population by Age and Gender
2010

Age Group (years)	Females	Males	Total	
	#	#	#	(%)
Less than 2	38,567	40,333	78,900	3
2-12	217,116	227,685	444,801	15
13-24	248,074	262,085	510,159	17
25-44	367,211	379,920	747,131	25
45-64	407,457	405,019	812,476	27
65 and older	259,611	193,277	452,888	15
Total	**1,538,036**	**1,508,319**	**3,046,355**	

Source: U.S. Census Bureau

Poverty, Health Insurance, and Employment

According to 2010 model-based estimates from the U.S. Census Bureau, 11.6% of Iowa's population was living below the poverty level, compared to the national average of 13.8%. This was an increase of 2.3% from 2002 estimates for Iowa residents. However, 14.2% of Iowa's youth 17 years or younger live in poverty, up from 10.9% in 2002.

Iowa's Health Insurance Gap

Approximately 12% of Iowa's residents are without health insurance. Those within the age group of 25 to 34 years were least likely of all age groups in Iowa to have health insurance, and males were 1.6 times as likely as females in that age group to be without insurance. Seventeen percent of those between the ages of 18 and 24 were without insurance, including 23% of males in this age group (Table 3).

Table 3
Percent Uninsured by Age
2011

Age group (years)	% Uninsured		
	Females	Males	Total
18-24	10.1	23.4	16.8
25-34	17.7	22.7	20.3
35-44	13.0	18.0	15.5
45-54	8.1	13.6	10.8
55-64	8.3	10.5	9.4
65-74	0.5	2.2	1.3
75 and over	0.5	0.1	0.4
Total adults	**8.9**	**14.5**	**11.7**

Source: Behavioral Risk Factor Surveillance System, Iowa Department of Public Health

Iowans who report lower household incomes are more likely not to have health insurance. Of people who reported an annual income of less than $15,000, 28% reported having no health insurance coverage. Less than 2% of people who reported an annual income of $75,000 or more did not have healthcare coverage (IDPH Behavioral Risk Factor Surveillance System, 2010).

Iowa's unemployment rate was reported at 6.0% for 2011, up from 4.3% in 2008 and compared to 9.7% nationally in 2011 (2011 Factbook, Legislative Fiscal Bureau, State of Iowa). In 2011, Iowa was ranked 7th lowest in the nation in unemployment. In Iowa, men experience a higher rate of unemployment than women (6.1% vs. 5.4%, respectively). The lower unemployment rate for women is due, in part, to women accepting part-time employment, temporary employment, and working out of their homes more often than men (Kahn, Iowa Workforce Development). Minority workers also experience a higher unemployment rate. In 2009, the total minority unemployment rate for Iowa was 14.0%, more than twice the rate of 6.0% for the total labor force.

Corrections

Iowa has nine state correctional facilities and a community-based correctional system. The prison inmate population at the nine correctional facilities increased by 202% from 1988 through 2007, but has since leveled off. There were 8,707 state inmates at the beginning of fiscal year 2011, which was a decrease of 30 inmates from FY 2008. There were just over 3,400 new admissions and 1,266 readmissions in FY2011. In addition, 4,800 offenders were released into the community during FY2011. The Criminal and Juvenile Justice Planning Division predicts that if criminal/incarceration practices remain the same, the prison population will reach 9,000 inmates by FY 2018. The population of prisoners was 116% of design capacity at the end of FY2010 (Department of Corrections; Iowa Legislative Factbook, 2011).

In 2011, the Iowa Department of Corrections reported that 56 offenders were HIV positive. In that year, 16 HIV-positive offenders were released from the prison.

The Sentencing Project Report

Uneven Justice: State Rates of Incarceration by Race and Ethnicity, a 2007 report by the Sentencing Project, reviewed rates of incarceration by race and ethnicity in all 50 states. Iowa was reported to have the most disproportionate rates of incarceration (per 100,000 population) between white and black persons of any state. The rate of incarceration per 100,000 population is nearly 14 times higher among blacks in Iowa than among whites. Only the District of Columbia has more disproportionate rates. Iowa ranked 10th among states for disproportionate rates of incarceration among Hispanic persons.

Substance Abuse

Drug-related prison admissions can be used as an indicator of drug abuse levels in the state. From 1995 to 2004, admissions for drug-related offenses (excluding alcohol-related offenses) increased by 248%, from 316 in 1995 to 1,110 in 2004. From 2004 to 2009, drug-related admissions decreased steadily, reaching a low of 693 admissions in 2009. Since then, admissions have begun increasing again. In 2011, there were 880 drug-related admissions. Both the decrease and the subsequent increases can be attributed to trends in methamphetamine lab incidents. The decrease was directly related to the passage of a 2005 state law restricting access to pseudoephedrine, a chemical used in the manufacture of methamphetamine[1]. Since 2008, however, methamphetamine lab incidents have increased.

Data from substance abuse treatment facilities in Iowa show that the number of persons treated for methamphetamine addictions peaked in FY 2004 at 14.6%, declined to 7.5% in FY2007, but has increased each year since. In FY2011, it was 9.6% (Table 4).

Convictions for methamphetamine use and crack cocaine use can greatly affect rates of incarceration by race and ethnicity. In Iowa, prison admissions related to crack cocaine rose from 85 offenders in FY2005 to 144 offenders in FY2008 while convictions for methamphetamine use were falling.[2] This has had an effect on the proportion of offenders who are black. As admissions for methamphetamine-related offenses fell, so did the proportion of new offenders who were white.

[1] Paul Stageberg. 2008. Iowa Prison Population Forecast FY2008-2018. Iowa Department of Human Rights, Division of Criminal and Juvenile Justice Planning.
[2] Ibid.

Methamphetamine use is more common among white persons, whereas crack cocaine use is more common among black persons. As a result, the percentage of black inmates in Iowa's prison system increased to 25% in FY2008. This has begun reversing with the increase in meth-related offenses since that time.

In FY2011, 1,093 of the 47,974 persons (2%) receiving treatment at a substance abuse treatment facility in Iowa reported injecting drugs at least once in the previous month. The majority of the injectors, 93%, was white, 3% were Hispanic, 3% were black, and 1% was American Indian or Alaskan Native. Polk County was the residence reported for 24% of the injection drug users admitted; Scott, Black Hawk and Linn counties each accounted for 7% of the injection drug users receiving treatment that year.

Table 4
Primary Drug for Clients in Treatment Programs
Iowa, FY 2000 – FY2011

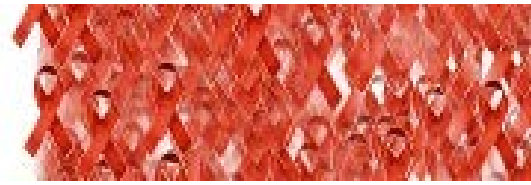
	Primary Problem – Type of Drug						
FiscalYear	Alcohol	Marijuana	Methamphetamine	Crack	Heroin	Other	Total Clients*
2000	62.3%	20.9%	9.4%	5.4%	.5%	1.5%	43,217
2001	60.5%	22.2%	10.7%	4.6%	.5%	1.5%	44,147
2002	58.5%	22.7%	12.3%	4.2%	.5%	1.8%	42,911
2003	57.5%	21.8%	13.4%	4.6%	.6%	1.9%	40,925
2004	55.6%	22.7%	14.6%	4.7%	.6%	1.8%	42,449
2005	55.8%	22.4%	14.4%	5.0%	.6%	1.9%	43,692
2006	55.9%	22.8%	13.6%	5.1%	.5%	2.2%	44,863
2007	58.3%	22.5%	10.7%	5.2%	.4%	2.9%	47,252
2008	61.9%	22.7%	7.5%	4.5%	.4%	2.9%	44,528
2009	61.4%	23.2%	7.8%	3.7%	.5%	3.4%	44,849
2010	58.6%	25.0%	8.8%	2.9%	.7%	4.0%	44,904
2011	55.2%	25.7%	9.6%	1.9%	.9%	6.7%	47,974

*Persons may be counted more than once if a client is later admitted for a different substance.

Mental Health

Statistics on the number of Iowans with disabilities vary, depending on definitions and methods used to produce them. The U.S. Census Bureau's American Community Survey found that in Iowa, an estimated 400,000 individuals have functional limitations. In other research, an estimated 700,000 Iowans experience at least some symptoms of mental disorder each year. Most never access the public service system, and data on the use of private pay services are lacking. Approximately 50,000 Iowans have intellectual or developmental disabilities. The same number is estimated to have brain injury. Data on the number of people with other types of disabilities are scant, for a variety of reasons. Access to services varies greatly, depending on the type of disability.[3]

[3] A Life in the Community for Everyone - The Department of Human Services Olmstead Plan for Mental Health and Disability Services: 2011 – 2015.



Iowa's Epidemic at a Glance

- *An average of 111 persons was diagnosed with HIV during each of the past 10 years, but the number of diagnoses increased by 3 persons per year during that period.*
- *In 2011, 120 Iowans were diagnosed.*
- *Males account for over 80% of HIV diagnosis since 2006. Sex with another male is the reported mode of exposure to HIV for 60% of males.*
- *Around half of people who are diagnosed with HIV receive an AIDS diagnosis within a year of HIV diagnosis (delayed or late testing).*
- *There were 64 persons known to be living with HIV or AIDS per 100,000 population as of December 31, 2011, an increase of 10.7 persons per 100,000 since December 31, 2008.*
- *The general population of Iowa is 2.8% black, non-Hispanic; and 5.0% Hispanic; however, 20% of HIV diagnoses were among black, non-Hispanic; and 13% were among Hispanics.*

Epidemiology of HIV, AIDS, and STDs in Iowa

HIV diagnoses increased by approximately 3 persons per year for the 10 years from 2002 through 2011. On average, 111 persons were diagnosed annually during this period, with a peak of 126 diagnoses in 2009. In 2011, 120 Iowans were diagnosed. Males have accounted for over 80% of HIV diagnoses since 2006. Sex with another male is the reported mode of exposure to HIV for 60% of males. By far, the greatest numbers of diagnoses occurred among persons 25 to 44 years of age. However, diagnoses among persons 13 through 24 years of age have been on the rise since 2007.

Black, non-Hispanic males; black, non-Hispanic females; and Hispanic males are over-represented among persons with HIV/AIDS when their population sizes are taken into account. Black, non-Hispanic males have HIV diagnosis rates more than eight times higher than white, non-Hispanic males. Hispanic males have rates over three times that of white, non-Hispanic males. Black, non-Hispanic females have the highest diagnosis rate among females, 18 times that of white, non-Hispanic females.

Diagnoses of AIDS peaked in 1992, coinciding with expansion of the CDC's definition of AIDS to include CD4+ cell counts less than 200 cells per milliliter or less than 14% of total lymphocytes. The introduction of highly active antiretroviral therapy (HAART) sparked a dramatic decline in AIDS diagnoses from 1995 through 1998. After reaching a low of 60 in 1998, the number of Iowa AIDS diagnoses increased to an annual average of 75 diagnoses from 2002 through 2011.

From 2002 through 2007 the state made steady progress in getting people diagnosed earlier in the course of the infection. The percentage of persons diagnosed with HIV that received an AIDS diagnosis within a year of HIV diagnosis (i.e., late testers) dropped from 59% in 2002 to 37% in 2007. However, since 2007, the proportion of late testers has been increasing, reaching 47% for persons diagnosed in 2010.

There were 21 deaths from all causes among Iowans with HIV/AIDS in 2010, the last year for which death ascertainment is complete. This was a sharp decline from 34 in 2007 and substantially less than the average of 29.3 from 2000 through 2009. Nineteen deaths have been reported so far for 2011. Death ascertainment for 2011 is incomplete pending linkage to state and national death registries.

The most significant feature of Iowa's HIV epidemic is the continual increase in the number of persons living with HIV and AIDS. Steady diagnoses of HIV infection, combined with widespread use of highly active, antiretroviral therapies that have delayed the onset of AIDS and decreased the number of deaths among persons with HIV/AIDS, have increased the number of persons living with HIV disease to unprecedented levels and have taxed limited resources for care and treatment.

The most significant feature of Iowa's HIV epidemic is the continual increase in the number of persons living with HIV and AIDS. Steady diagnoses of HIV infection, combined with widespread use of highly active, antiretroviral therapies that have delayed the onset of AIDS and decreased the number of deaths among persons with HIV/AIDS, have increased the number of persons living with HIV disease to unprecedented levels and have taxed limited resources for care and treatment. As of December 31, 2011, there were 1,939 Iowans reported to be living with HIV or AIDS. Another 509 were estimated to be infected but not diagnosed, bringing the estimated number of infected persons to 2,448. There were 64 persons known to be living with HIV or AIDS per 100,000 population as of December 31, 2011, an increase of 10.7 persons per 100,000 since December 31, 2008. While the ten most populous counties (Black Hawk, Dallas, Dubuque, Johnson, Linn, Polk, Pottawattamie, Scott, Story, and Woodbury) account for 49% of the total population of Iowa, 74% of persons living with HIV/AIDS were diagnosed as residents of those counties. Polk, Scott, Johnson, Pottawattamie, Woodbury and Black Hawk counties all have numbers of persons living with HIV/AIDS that are above the state average.

Introduction to Iowa's HIV Service Delivery System

Private physicians and medical providers are important deliverers of HIV services like testing and treatment in Iowa. A majority of diagnoses is made through this service delivery system, and many people living with HIV who have insurance or the means to provide for their own care choose to work with private physicians to manage their HIV disease.

As with most healthcare systems, however, there remain gaps in services among people with low incomes, people living in rural areas without access to specialized care, and people who do not access traditional medical care for a number of reasons. **Medicare and Medicaid** are two governmental health insurance programs that help address the healthcare gaps for low-income people living with HIV. Medicare is administered by the federal government, and Medicaid is funded by both the federal and state governments. In Iowa, Medicaid is managed by the Iowa Medicaid Enterprise, a division of the Iowa Department of Human Services. Both programs have specific eligibility criteria. These programs are discussed later in this publication. In addition to these two governmental insurance programs, veterans may receive healthcare through the U.S. Department of Veterans Affairs. Iowa has two Veterans Affairs Medical Centers that treat people with HIV, one in Des Moines and one in Iowa City.

The Iowa Department of Public Health's Bureau of HIV, STD, and Hepatitis also has funding to address gaps in services by providing access to medications and by supporting agencies to provide testing, case management, and other prevention and supportive services. IDPH collaborates with local health departments and community-based organizations to deliver the following services throughout the state:

- Free HIV counseling and testing services;
- Health education and risk reduction (HE/RR) activities;
- Services for newly diagnosed people, including counseling, testing of partners, and referrals to care;
- Essential health and support services, including medications, to low-income HIV-infected individuals;
- Collection, analysis, and dissemination of data on the HIV/AIDS and STD epidemics in Iowa;
- STD testing and treatment medications at 70 clinics across the state;
- Hepatitis C testing and Hepatitis A and B immunizations for persons at risk for these diseases.

Another key component of Iowa's service delivery system that addresses gaps in care is the **Ryan White Part C Early Intervention Services** funded through the Health Resources and Services Administration (HRSA). Three community health centers (in Davenport, Des Moines, and Sioux City) and one university medical center (in Iowa City) are funded in Iowa to provide primary healthcare for low-income people living with HIV in outpatient settings. Another university medical center in Omaha, NE, receives Part C funds and serves Iowans who live near Omaha. Medical

evaluation and clinical care are covered through the Part C service providers as well as antiretroviral therapy, and the prevention of opportunistic infections.

The final main category of services in Iowa is the **Housing Opportunity for People with AIDS** (HOPWA) program. HOPWA funds are provided by the U.S. Department of Housing and Urban Development (HUD) to the Iowa Finance Authority (IFA). The State of Iowa has five HOPWA project sponsors[4] funded under the HUD grant. These five project sponsors are located in geographic locations in the state that provide services to all ninety-nine counties of Iowa.

Coordinated Planning: Iowa's HIV Community Planning Group

Implementation of the *Iowa Comprehensive HIV Plan* requires broad-based community participation. Accordingly, the Iowa HIV Community Planning Group (CPG) is responsible for maintaining and implementing the ongoing planning process.

Iowa's HIV Community Planning Group is a valuable resource for ensuring the HIV planning process is a broad and inclusive one. Membership of the CPG includes people living with HIV; people who represent marginalized and underserved populations at high risk for HIV; Ryan White Part B, C, and F providers; prevention service providers; HOPWA providers; social science experts; representatives from corrections, substance abuse and mental health; and others with related expertise. The diversity of CPG representation provides IDPH and other coordinating entities direct access to community input and expertise.

The Iowa planning process embraces parity and inclusion and participatory community planning as essential components for building effective statewide HIV prevention and care programs. To facilitate planning in Iowa, the IDPH selects an employee or a designated representative as one co-chair, and the CPG selects a community co-chair. The co-chairs share responsibility for guiding the CPG in accomplishing its mission and goals.

To accomplish the tasks identified by the CPG, smaller working groups, or committees examine issues and develop recommendations more productively. The CPG currently has nine committees:

1) the Membership, Orientation and Bylaws Committee (MOB);
2) the Epidemiological Profile and Information Committee (EPIC);
3) the Needs Assessment/Community Resources Committee (NARC);
4) the Care Assessment and Strategic Access Committee (CASA);
5) the Strategies for Prevention Interventions and Community Endeavors Committee (SPICE);
6) the Quality Assurance and Case Management Standards Committee (QUAC);

[4] http://www.iowafinanceauthority.gov/documents/resources/HOPWA_County_Number_Map_F62C35710E66E

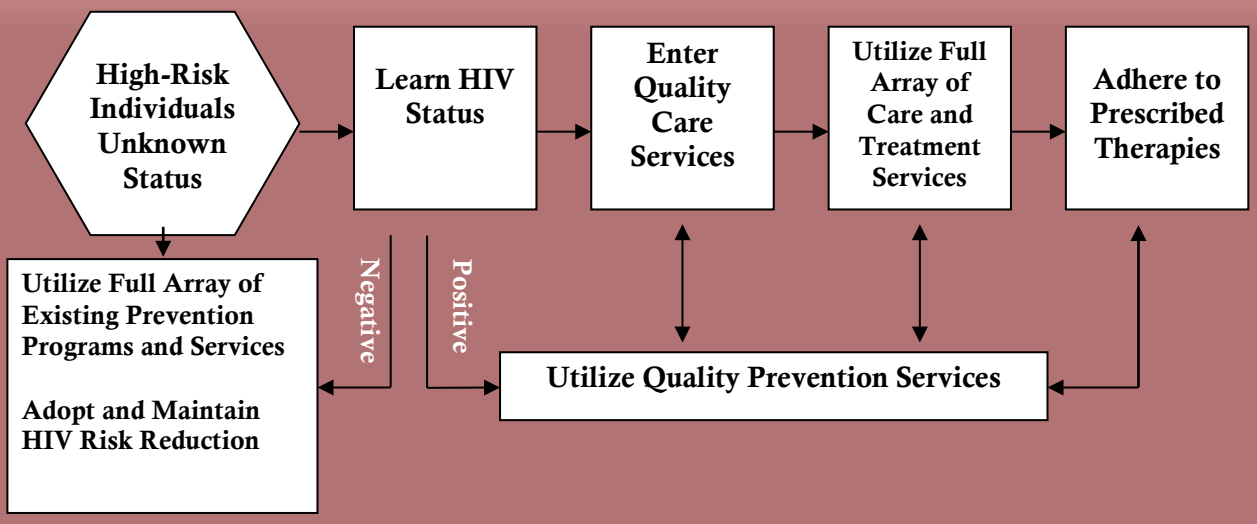
7) the Public Relations (PR) Committee, the Racial, Ethnic, and Health Disparities Committee (REHD); and
8) the Take A Stand Committee (TASC) for men's health.

Committee members select a chair for each committee.

Once the comprehensive plan is finalized, the process does not end for CPG. In fact, the CPG is involved in the ongoing monitoring and implementation of the plan. It also helps to advise IDPH staff and to determine necessary changes in strategy or goals based on emerging issues or trends.

Continuum of Prevention-Care-Prevention (Former Model)
Until recently, IDPH and the CPG has utilized a "prevention-care-prevention" model (Figure 3) for structuring a continuum of prevention and care. This was developed as Iowa began to make a concerted effort to recognize and make best use of the intersections of prevention and care.

Figure 3 Prevention Care Prevention Continuum



With the above model, Iowa placed significant focus on testing for high-risk individuals of unknown HIV status. Then, depending on the test result, the focus was on evidence-based HIV prevention interventions for people who tested negative, or care services for individuals who tested HIV-positive. HIV-positive individuals who were at risk for transmitting HIV were also recruited to participate in prevention interventions tailored to the needs of PLWHA.

Focus on HIV Prevention

In 2011, the Centers for Disease Control and Prevention announced a new five-year HIV prevention funding opportunity for health departments in states, territories, and select cities. Providing funding to health departments has long been a central component of CDC's HIV prevention strategy, and is the agency's single largest investment in HIV prevention. This new funding opportunity represented a new direction in HIV prevention, and was designed to "achieve a higher level of impact with every federal HIV prevention dollar."[5]

According to the CDC, the "new approach features better geographic targeting of resources and a stronger focus on supporting the highest-impact prevention strategies. This approach embodies CDC's commitment to high impact prevention using scalable, cost-effective interventions with demonstrated potential to reduce new infections to yield a major impact on the HIV epidemic. High impact prevention is essential to achieving the HIV prevention goals of the National HIV/AIDS Strategy, which was announced in 2010."[6]

Health departments were invited to submit proposals for Comprehensive HIV Prevention Programs in the following three categories:

Category A: HIV Prevention Programs for Health Departments *(core funding)*
Category B: Expanded HIV Testing for Disproportionately Affected Populations *(limited eligibility and optional)*
Category C: Demonstration Projects to Implement and Evaluate Innovative, High Impact HIV Prevention Interventions and Strategies *(competitive and optional)*

Iowa did not qualify for Category B funding, however, it applied for categories A and C. It received funding only for Category A. With these funds, Iowa's HIV Prevention Program will consist of the following elements:

Counseling Testing and Referral (CTR) Services

Testing is targeted to populations with a high prevalence of and/or a disproportionate impact from HIV. The following populations have been prioritized by the CPG as high-risk or disproportionately impacted populations:

- Men Who Have Sex with Men (MSM),
- Black/African-Americans;
- High-Risk Heterosexuals (HRH);
- Hispanic/Latinos; and
- Injection Drug Users (IDU).

[5] http://www.cdc.gov/hiv/topics/funding/PS12-1201/
[6] http://www.cdc.gov/hiv/topics/funding/PS12-1201/

IDPH currently contracts with 11 agencies to provide confidential HIV and HCV counseling, testing, and referral (CTR) services and adult hepatitis A and B immunizations. The department also holds memoranda of agreement (MOAs) with two additional agencies that receive rapid test kits and have the use of the client-level data collection system, EvaluationWeb.

IDPH-supported Test Sites

AIDS Project of Central Iowa, Des Moines
Black Hawk County Health Department, Waterloo
Cerro Gordo County Health Department, Mason City
Council Bluffs Health Department, Council Bluffs
Hillcrest Family Services, Dubuque
Johnson County Public Health, Iowa City
Linn County Public Health, Cedar Rapids
Mental Health Institute, Mt. Pleasant
Polk County Health Department, Des Moines
Scott County Health Department, Davenport
Siouxland Community Health Center, Sioux City
Siouxland District Health Department, Sioux City
Webster County Public Health, Fort Dodge

Efforts to identify newly infected persons have been improved by raising standards and performance measures for contracted agencies to reach high-risk and disproportionately impacted populations. In 2010, agencies worked toward ensuring that 80% of all HIV tests administered to persons from high-risk or disproportionately impacted populations. As a means to achieve this, contracted agencies have improved accessibility to services by extending service hours and increasing outreach efforts. In addition to increased standards and expectations, contractors have been and continue to be provided ongoing training regarding the role of social determinants of health in predicting who is at risk and in increasing risk or the likelihood of transmission among certain populations. The provision of test results has been greatly improved by the use of rapid HIV testing technology that enables the test to both be conducted and results to be delivered within a single visit. This ensures receipt of test results and also increases portability of testing, thereby improving accessibility to people from rural areas.

IDPH test sites require that counselors are trained through the Fundamentals of HIV Prevention Counseling course. It is during this training process that counselors are taught to assess client risk and provide risk-reduction counseling and referrals to meet additional needs. Trainees also learn to integrate hepatitis and STD education and risk screening as well as other referrals into the counseling sessions. Most importantly, counselors are trained to link people who are confirmed HIV-positive to medical care and support services.

Partner Services (PS)

Partner Services is a program in which highly trained individuals, known as Disease Prevention Specialists (DPS), offer assistance to persons newly diagnosed with HIV or other STDs in notifying their sex and needle-sharing partners of their exposure. DPS interview newly diagnosed individuals and elicit information about their partners within a specific timeframe. This information is used to locate and notify partners confidentially of their exposure so

that they may be linked with medical care for testing and treatment. If the original patient prefers, he or she may notify partners directly with assistance from the DPS. The Partner Services program is voluntary, and DPS uphold the strictest standards of confidentiality. DPS also counsel patients on how to manage their infection and how to reduce the risk of complications or transmitting the infection to others. DPS also have access to a wide range of other resources to which they can refer the patient for additional assistance, as needed.

The State of Iowa employs six DPS who serve individuals in six different geographical regions in Iowa. Additionally, there are four counties in Iowa that employ their own DPS who serve individuals in their particular counties. These four counties are Polk, Black Hawk, Linn, and Scott. Although DPS in these four counties are employed by their county health departments rather than the Iowa Department of Public Health (IDPH), they all work closely with IDPH's Partner Services program and the six state DPS. Together, the state and county DPS are able to cover all of Iowa and offer Partner Services to individuals infected with HIV or many other STDs, thus improving both the health of individuals and the public.

Evidence-based Behavioral Prevention Interventions

Evidence-based interventions (EBIs) are CDC-approved curricula used in health education and risk reduction (HE/RR) programs. They help high-risk and/or disproportionately impacted populations reduce the risk of becoming HIV-infected or, if already infected, of transmitting the virus to others. An RFP was issued in 2009 to deliver HE/RR activities, including EBIs, to target populations from 2010 to 2014. Nine projects were funded to provide 22 interventions during 2010 and 2011. These interventions were selected based on their applications to reach communities of color, men who have sex with men, and other populations facing HIV-related health disparities. One agency also received direct funding from CDC for prevention with MSM (see below).

Due to the substantial reduction of CDC HIV prevention funds as part of the IDPH's new cooperative agreement with CDC, the IDPH-funded HE/RR contracts were ended after 2011. Only two agencies (using three EBIs) could be funded in 2012. These projects address HIV-positive persons and MSM in central Iowa and HIV-positive persons in northwest Iowa. These are one-year projects, and IDPH is unlikely to be able to continue HE/RR activities after 2012 without additional funding or reprioritization/ redirection of prevention efforts.

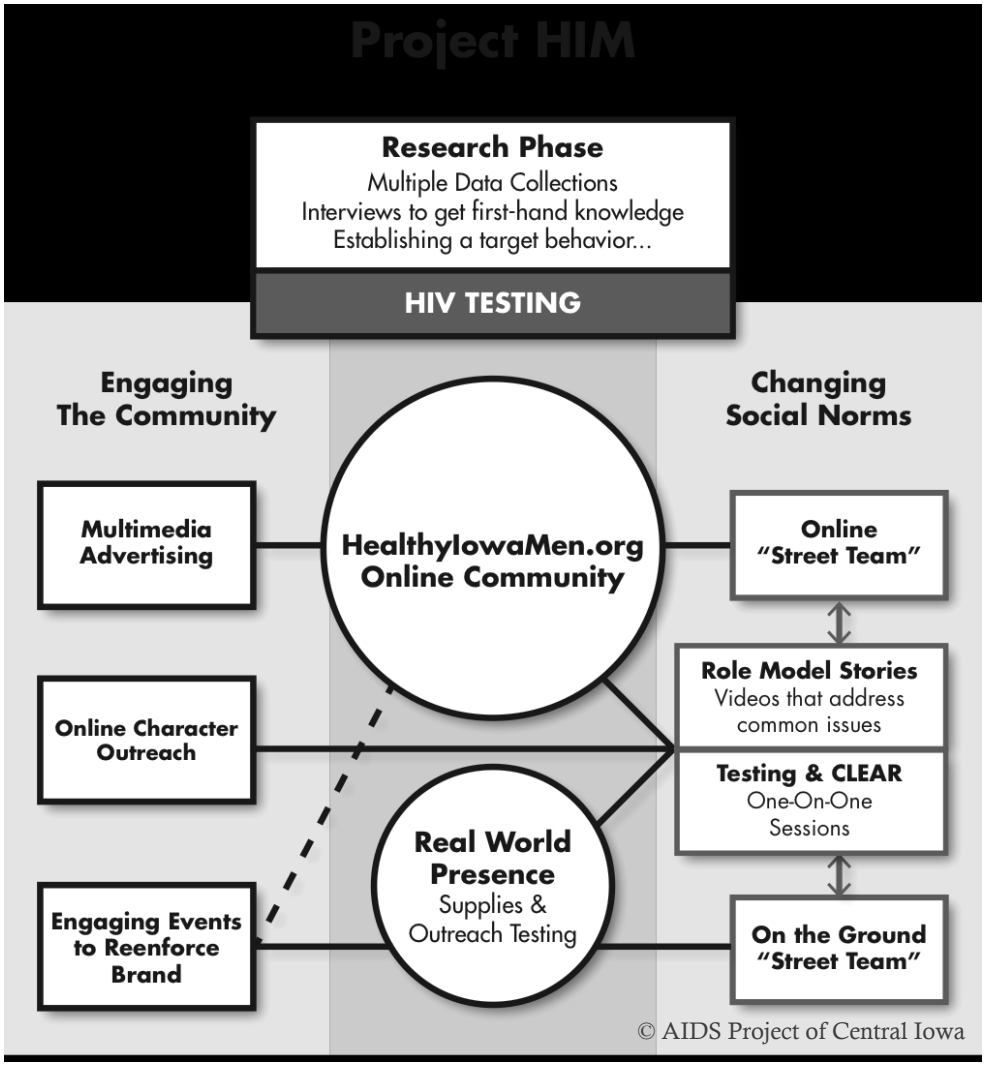
2012 IDPH-funded HIV Prevention Projects

HIV-positive Persons
- AIDS Project of Central Iowa, Des Moines
- Siouxland Community Health Center, Sioux City

MSM
- AIDS Project of Central Iowa, Des Moines

Prevention Projects Using Other Funding

Project HIM (Healthy Iowa Men) is an online prevention initiative based out of the AIDS Project of Central Iowa in Des Moines. The project works to change norms related to routine HIV testing among gay, bi, and transgender men. Funding comes directly from CDC as part of the Funding Opportunity Announcement PS10-1003: HIV Prevention Projects for Community-based Organizations. The initiative is based on the behavioral intervention, Peers Reaching Out and Modeling Intervention Strategies (PROMISE). This community-level intervention is based on several behavior change theories. A community assessment process is conducted, peer advocates are recruited and trained from the target population, role model stories are written from interviews with the target population, and these stories are distributed along with other risk reduction materials to target audiences to help people move toward safer sex or risk reduction practices.



Foundational to this project is a dynamic, multimedia-intensive website, www.healthyiowamen.org. The site features accurate and up-to-date information and resources on all components of gay and bi men's wellness—physical health, emotional health and relationships, sexual health, and spirituality. Project HIM staff work with top local GBT professionals, including the most prominent gay physician in Central Iowa, one of the only certified sex therapists in the state, and an outstanding mental health therapist who's served the GBT community for more than 15 years, to write articles and answer guys' questions. Three diverse illustrated characters represent Project HIM online. These characters were created by a nationally-recognized gay Iowa illustrator. The characters appear on various GBT-oriented social and dating sites to answer user questions. Each character's weekly blog is showcased on the Project HIM site to detail their triumphs and struggles with life and relationships. The blog invites the GBT community and its allies to unite and share personal stories about any project related to healthy living—anything from starting an exercise routine to seeking counseling to having a

medical check-up. Also, YouTube videos feature various individuals from Iowa's GBT community showcase influential narratives of making positive changes in their wellness.

Mpowerment Iowa City is a community–level approach to HIV prevention for men who have sex with men (MSM) in the Iowa City and Cedar Rapids metropolitan areas. It is funded by Johnson County Public Health. The project focuses on creating opportunities for MSM to socialize in a safe atmosphere. HIV prevention and safer-sex messages are disseminated via social events by project staff. Participants in the project are trained to act as lay health advisors and disseminate HIV prevention and safer-sex messaging through their personal social networks. The project is an implementation of the Mpowerment Project, an intervention scientifically proven to reduce rates of unprotected anal intercourse and HIV transmission among MSM. In 2011, 899 contacts were made through informal outreach and 21 MSM attended M-groups to discuss factors contributing to infrequent or no HIV testing and unsafe sex among the men (e.g., increasing motivation for frequent HIV testing, meeting partners online, beliefs that safer sex is not enjoyable, and poor sexual communication skills). Through skills-building exercises, the men practice safer sex negotiation and correct condom use skills. They are also trained to conduct informal outreach.

Iowa's PREP (Personal Responsibility Education Program) provides sexuality education to adolescents that is medically accurate, culturally and age-appropriate, and evidence-based. The program is administered by the Bureau of Family Health at IDPH, and funded by the U.S. Department of Health and Human Services' Administration for Children and Families. It has the goal of assisting youth to reduce their risk of unintended pregnancy, HIV/AIDS, and other sexually transmitted infections. Iowa PREP also addresses risk and protective factors to assist teen in making responsible, informed decisions to lead safe and healthy lives.

Iowa PREP has five grantees delivering services in seven Iowa counties. The grantees are delivering the Teen Outreach Program (TOP), Wise Guys, and SiHLE (Sisters Informing, Healing, Living, Empowering) to youth in their area through school and community-based groups. Additional adulthood preparation subjects that are covered in conjunction with the curriculum include healthy relationships, adolescent development, and healthy life skills.

> **The TOP® program** empowers teens to lead successful lives and build strong communities. The evidence-based curriculum, Changing Scenes© includes information on values, relationships, communication, influence, goal-setting, decision-making, and sexuality and human development. The one unique addition to TOP® is community service learning. Youth participate in 20 hours over the 9-month implementation period. PREP grantees implementing TOP include the Cerro Gordo County Department of Public Health and Planned Parenthood of the Heartland (Woodbury and Des Moines Counties).
>
> **The Wise Guys®** curriculum model is designed to prevent adolescent pregnancy by reaching out to adolescent males through a 10-week program. The evidence-based curriculum includes,

but is not limited to, lessons on values, communication, dating violence, sexuality, decision-making, and abstinence and contraception. PREP grantees implementing Wise Guys® include Bethany for Children and Families (Scott County), Planned Parenthood of the Heartland (Pottawattamie County), and Women's Health Services of Eastern Iowa, Inc. (Clinton County).

The SiHLE intervention is a small group, skills training intervention to reduce risky sex behavior among African–American adolescent females. Through interactive discussions in groups of 10 to 12 girls, the intervention emphasizes ethnic and gender pride, and enhances awareness of HIV risk reduction strategies such as abstaining from sex, using condoms consistently, and having fewer sex partners. The PREP grantee implementing SiHLE is Allen Women's Health (Black Hawk County).

Focus on HIV Care

The major barrier to healthcare access for most people is cost. Nearly one in five Americans reports needing healthcare but being unable to afford it. This is principally because of a lack of health insurance or other payer of healthcare services, such as Medicaid or Medicare. Currently, fewer than one in five (17%) people living with HIV has private insurance and nearly 30% do not have any coverage.[7] To provide better access to health insurance and healthcare, Congress passed the Patient Protection and Affordable Care Act (PPACA) in 2010. The goals of the PPACA are to reduce costs associated with healthcare, to improve quality of healthcare, and to improve access to healthcare through affordable health insurance coverage. It works with public healthcare programs, such as Medicaid and Medicare, and with private health insurance networks to change healthcare delivery in the United States. This landmark legislation and its impacts on the delivery of HIV care are discussed below.

The Patient Protection and Affordable Care Act of 2010

Passed in March 2010, the Patient Protection and Affordable Care Act (generally referred to as the Affordable Care Act or ACA) expands access to insurance coverage for low-income PLWHA through a number of important provisions. It removes the ability of insurance providers to deny coverage because of pre-existing health conditions like HIV. It also establishes standards for basic health-benefit packages, including important preventive health screenings and assessments, and it seeks to improve the quality of healthcare for people living with HIV. Provisions of the ACA will be phased in over time, with the most significant changes occurring after 2013.

[7] http://aids.gov/federal-resources/policies/health-care-reform/

As of September 23, 2010, insurers were no longer able to deny coverage to children living with HIV or AIDS, they were prohibited from cancelling coverage to their customers unless the customer had submitted a fraudulent application, and they had to remove lifetime caps on insurance benefits. States were also awarded funds to create pre-existing condition insurance plans (PCIPs) for uninsured people with pre-existing chronic conditions. The PCIPs were temporary measures until permanent expansions of Medicaid and health insurance coverage began in 2014. If a state opted not to operate the PCIP, a federal plan was available to the citizens of that state. Iowa received $35 million to operate its PCIP. States were given the option to disallow third-party payers for the premiums, meaning that each enrollee had to pay his or her own premiums. Iowa was one of a handful of state-run PCIPs that did not allow for third-party payers. This meant that the IDPH AIDS Drug Assistance Program, which offers assistance with insurance premium payments for those who qualify for ADAP, could not pay the PCIP premiums for its ADAP enrollees. This eliminated access to the PCIP for hundreds of people living with HIV on the state's ADAP. Members of the legislature and HIV advocates in the state attempted to have this exclusion removed. As of this time, these efforts have not been successful.

In 2014, there were to be significant expansions in access to healthcare. By 2014, states must have established health insurance exchanges where people can compare and purchase affordable health insurance policies that include the basic health-benefit package. Similar to the PCIPs, if the state opts not to establish an exchange, the federal government will create the exchange. People with incomes less than 400% FPL will be eligible for tax subsidies that will help them buy coverage through the exchange. At the same time, the Affordable Care Act broadens Medicaid eligibility to include individuals with incomes below 133% of the Federal Poverty Level ($14,400 for an individual and $29,300 for a family of 4), including single adults who have not traditionally been eligible for Medicaid benefits before. As a result, an adult living with HIV who meets this income threshold no longer has to wait for an AIDS diagnosis in order to become eligible for Medicaid.[8] Only citizens and legal immigrants are eligible for the expansion programs.

By 2020, the Affordable Care Act will also result in the phasing out of the "donut hole," which has been a major barrier within the *Medicare Part D* prescription drug benefit.[9] The donut hole refers to the gap in coverage for medications once a Medicare Part D recipient surpasses the drug coverage limit. The recipient is then responsible for all medication costs until he or she reaches the catastrophic coverage threshold. At that time, the program once again pays for all medications. Beginning in 2011, the ACA allowed ADAP expenditures to be counted as patient out-of-pocket costs. This allowed ADAP enrollees with Medicare Part D to move more quickly through the coverage gap and reach the catastrophic coverage threshold.

The implementation of the ACA centers on a controversial requirement for all citizens to purchase health insurance or to be enrolled in a governmental program like Medicaid or Medicare. In June 2012, the Supreme Court ruled on a number of challenges to the ACA, including the mandate for individual insurance coverage. The requirement for health insurance was upheld by the Court, but it was ruled that the federal government could not require states to expand Medicaid coverage.

[8] http://aids.gov/federal-resources/policies/health-care-reform/

[9] Beneficiaries who reached the donut hole in 2010 will receive a one-time rebate of $250. In 2011, these beneficiaries will receive a 50% discount on brand-name drugs while they are in the "donut hole," a considerable savings for people taking costly HIV/AIDS drugs. In addition, *ADAP* benefits will be considered as contributions toward Medicare Part D's true Out of Pocket Spending Limit ("donut hole"), a huge relief for low-income individuals living with HIV and AIDS.

Medicaid is funded jointly by the federal and state governments. The expansion is to be funded fully by the federal government for the first three years, then the federal share would decrease to 95%, and finally to 90% beginning in 2020.

Much remains unknown about the implementation of the Affordable Care Act, particularly in states where the Governor and/or legislature oppose the law. Iowa's Governor, Terry Branstad, recently issued a statement indicating that he would decline federal funds related to the expansion of Medicaid. Governor Branstad has expressed concern about the Federal government's ability to continue to fund the expansion and worries that the burden to pay for the program will be shifted to states. At this time, it is unclear what options will be made available to persons who would have been eligible for the Medicaid expansion if the state does not accept the Medicaid expansion funds.

Medicaid

Medicaid, the nation's principal safety-net health insurance program for low-income Americans, has played a critical role for people with HIV from the early days of the AIDS epidemic in the 1980s and has remained so ever since. Medicaid is estimated to be the single largest source of coverage for people with HIV in the U.S., and to account for more than half of all spending on HIV care by the federal government (including the state share of Medicaid spending).

To qualify for Medicaid, individuals must be low-income and part of a group that is "categorically eligible." At this time, low-income, childless adults are not eligible for Medicaid unless they are disabled (see disability definition in Table 5). Although there are several paths to Medicaid eligibility, people with HIV may have trouble meeting eligibility requirements because having HIV does not automatically qualify as a disability, even if the infected person meets income guidelines.


IOWA DEPARTMENT OF HUMAN SERVICES
MEDICAL ASSISTANCE ELIGIBILITY CARD
Month Valid
Year
Aid–Type
County
PERSON ID:
RESTRICTED COVERAGE
PROVIDER TYPE
NUMBER
BIRTHDATE:
OTHER INS:
VALID FOR
SERVICES NOT LISTED UNDER RESTRICTED COVERAGE
NAME:
Member Services Call Center 1-800-338-8366
In the Des Moines area, call 725-1003

However, in Iowa, low-income, childless adults may qualify for a Medicaid expansion program entitled IowaCare. This Section 1115 Waiver program provides catastrophic medical coverage (see Table 5). Additionally, the Medicaid Home and Community Based Services Acquired Immunodeficiency Syndrome/Human Immunodeficiency Virus Waiver (HCBS AIDS/HIV) provides service funding and individualized supports to maintain eligible members in their own homes or communities who would otherwise require care in a medical institution.

In Iowa, Medicaid is a critical source of coverage for many low-income Iowans living with HIV. According to the Kaiser Family Foundation, there were 566 Iowa Medicaid enrollees with HIV in FY2009 (approximately 32% of Iowans living with HIV/AIDS in 2009). The total state Medicaid spending on enrollees with HIV that year was $7,047,654.00 or $12,452 per capita.[10] This is among the lowest per capita cost for any state.

[10] Kaiser Family Foundation, Medicaid and HIV: Iowa: Medicaid Enrollment and Spending on HIV, FY2009.

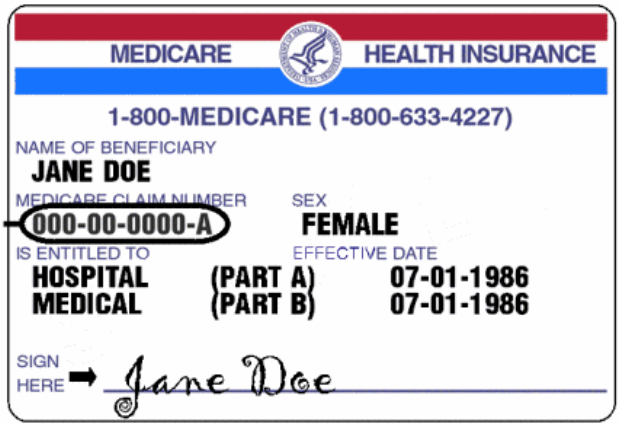
Table 5 Pathways to Medicaid Eligibility For People with HIV/AIDS in Iowa	
Category	**Criteria**
Supplemental Security Income (SSI) Beneficiaries	**Disabled (having a physical or mental impairment that prevents one from working for a year or more or that is expected to result in death) AND low-income**
Parents, children, pregnant women	**Pregnant women or parent with dependent children under the age of 18 that meet income and resource eligibility**
Medically Needy	**Allows those who meet categorical eligibility, such as disability, to spend down on medical expenses to meet state's income criteria**
Disabled workers (Medicaid for Employed People with Disabilities-(MEPD))	**Disabled; Low-income**
IowaCare Program (Medicaid expansion)	**Must receive medical care at the medical home designated within the patient's county of residence and meet income eligiblity.** http://www.ime.state.ia.us/IowaCare/
State Supplementary Payment (SSP)	**Disabled, receive SSI or meet exceptions, and receive SSP**

Medicare

According to the Kaiser Family Foundation, "Medicare, the federal health insurance program for people age 65 and older and younger adults with permanent disabilities, is an important source of health coverage for an estimated 100,000 people with HIV."

The program covers approximately one fifth of people with HIV estimated to be receiving care in the United States[11], but PLWHA account for only a relatively small fraction (<.01%) of the overall 49 million persons in Medicare.

At this time, Medicare provides broad coverage of basic healthcare service but has high cost-sharing requirements, no cap on out-of-pocket spending, and doesn't cover long-term care. In January 2006, Medicare began offering a prescription drug benefit for the first time, called Medicare Part D. Although this new benefit saved the Iowa ADAP money, the amount is not significant. Over 85% of Iowa HIV/AIDS Medicare beneficiaries are also eligible for Medicaid.



[11] Kaiser Family Foundation. HIV/AIDS Policy Fact Sheet: Medicare and HIV; February 2009.

The Affordable Care Act will have a great influence on Medicare and how people living with HIV access healthcare services. According to the Kaiser Family Foundation[12], the Act includes a number of provisions that affect Medicare, including enhanced benefits (prevention benefits and phasing out the Part D coverage gap called the donut hole), spending reductions affecting plans and providers, delivery system reforms, premium increases for higher-income beneficiaries, and a payroll tax on earnings for higher-income individuals. At this time, although care providers are aware that change is on the horizon, details of these modifications are not yet known.

Table 6 Pathways to Medicare Eligibility for People with HIV/AIDS

Eligibility Category	Eligibility Criteria
Individuals age 65 and older	Sufficient number of work credits to qualify for Social Security payments
Individuals under age 65 with permanent disability	Sufficient number of work credits to qualify for SSDI payments due to disability; and Have been receiving SSDI payments for at least 24 months
Individuals with end-stage renal disease, any age	Sufficient number of work credits to qualify for Social Security payments

Forecasting growth in the number of Medicare beneficiaries with HIV/AIDS is difficult. On one hand, the number may grow as more people with HIV/AIDS live longer; on the other, the success of combination antiretroviral therapy may keep people with HIV from meeting the SSDI eligibility criteria to receive Medicare coverage.

Ryan White HIV/AIDS Treatment Extension Act of 2009

The Ryan White Program is administered by the U.S. Department of Health and Human Services (HHS) through the Health Resources and Services Administration (HRSA), and is the largest federal program focused exclusively on HIV/AIDS care. The program is for individuals living with HIV/AIDS who have no health insurance (public or private), have insufficient healthcare coverage, or lack financial resources to get the care they need for their HIV disease. As such, the Ryan White Program fills gaps in care not covered by other funding sources.

The legislation is called the *Ryan White HIV/AIDS Treatment Extension Act of 2009* (Public Law 111-87, October 30, 2009). The legislation was first enacted in 1990 as the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act. It has been amended and reauthorized four times: in 1996, 2000, 2006, and 2009. The Ryan White legislation has been adjusted with each reauthorization to accommodate new and emerging needs, such as an increased emphasis on funding of core medical services and changes in funding formulas.

The Ryan White Program is divided into multiple "parts" that fund different categories of services. The majority of Ryan White funds in Iowa support primary medical care (Part C) and essential support services (Part B). A smaller but equally critical portion funds technical assistance, clinical training, and research on innovative models of care (Part F).

Iowa has a Part B program (which includes ADAP and support services), four Part C programs, and a Part F program.

[12] http://www.kff.org/medicare/upload/8354.pdf

Ryan White Part B Client Services

The Iowa Department of Public Health is the state's grantee for the Part B program. The grant consists of a base award, the AIDS Drug Assistance Program (ADAP) award, and an ADAP supplemental award.

Part B provides funding to cover core medical services including:

- Outpatient and ambulatory health services;
- ADAP;
- Oral health care;
- Early intervention services;
- Health insurance premium and cost-sharing assistance;
- Medical nutrition therapy;
- Mental health;
- Outpatient substance abuse care;
- Medical case management; and
- Treatment adherence services.

Support services funded through Part B include:

- Outreach services;
- Non-medical case management;
- Psycho-social support;
- Medical transportation;
- Linguistic services; and
- Referrals for healthcare and support services.

How Does ADAP Benefit Iowa?

With the availability of effective treatments:

- People with HIV are living longer, healthier lives, and are remaining contributing members of their communities;
- The number of hospital visits is reduced, the onset of disabilities is delayed, and the burden on the Medicaid program is decreased; and
- Patients' viral loads are lowered, which reduces the risk of HIV transmission.

Congress designates, or "earmarks," a portion of the Part B appropriation specifically for the ADAP. This distinction is important because other Part B spending decisions are made by each state or territory. Five percent of the total national earmark, however, is reserved for supplemental grants to states and territories that have demonstrated severe need. Iowa ADAP has historically operated a 'bare bones' program and has received supplemental funding since 2006.

The Iowa ADAP provides life-saving drugs for low income, HIV-positive Iowans without health insurance. It also pays for health insurance premiums, co-pays, and deductibles for eligible clients. As of December 2012, nearly 800 Iowans (approximately 25% of the people diagnosed and living with HIV/AIDS in the state) were enrolled in Iowa's ADAP. To be eligible for the program, individuals have to make less than 200% of the Federal Poverty Level. However, a $500 per month work allowance for employed persons is permitted.

Pressure on ADAP resources increases substantially every year. Over the past 10 years, Iowa ADAP has had to close the program to new enrollees and implement a waiting list on two occasions. The

first closure occurred in 2004 and the second in 2009. Program closures were fourteen and sixteen months long, respectively, and corresponded with a rise in ADAP program closures nationwide. In both cases, the program was able to reopen due to emergency funding from state (2004) or federal (2009) sources.

The most significant reasons for the insufficient funding of ADAP's across the country and in Iowa:

- Increasing costs of highly active antiretroviral therapy (HAART), the standard of care for a majority of people living with HIV disease. In addition, people living with HIV/AIDS face costs of treating opportunistic infections, managing side effects, and addressing other treatment issues.
- Decreasing AIDS mortality with a steady number of new infections. An estimated 50,000 new infections occur annually in the United States. Therefore, the total number of people living with HIV disease continues to climb.
- A growing epidemic among minorities, who have historically experienced higher risk for poverty, lack of health insurance, comorbidity, and disenfranchisement from the healthcare system. The result is a growing number of PLWHA who require public support.
- A continued economic crisis that includes high rates of unemployment, which causes more PLWHA to rely on public health safety-net programs, including ADAP, as a vital source for medications.[13]
- Funding that has not kept pace with the demand. In particular, state funding for the ADAP in Iowa has decreased since the original allocation of $555,000 in state FY2006.

The Iowa Department of Public Health's Ryan White Part B Program contracts with 12 agencies to provide supportive services throughout the state. Contractors provide essential health and supportive services to financially eligible clients living with HIV. All Ryan White programs are "payers of last resort," meaning that all other resources, including Medicaid and Medicare, need to be exhausted before an applicant is eligible. Ryan White supportive services include case management, both medical and non-medical, and financial assistance for mental health services, substance abuse services, doctor and dental bills, linguistic services and transportation expenses. In 2011, more than 1,100 persons living with HIV received services through the Ryan White Part B Client Services Program. The IDPH publicizes services to healthcare and social service providers throughout Iowa.

Eligible Iowans living with HIV may go to any of the following Part B contractors for assistance:

- Siouxland Community Health Center, Sioux City
- Nebraska AIDS Project, Omaha, Nebraska
- AIDS Project of Central Iowa, Des Moines
- Webster County Health Department, Ft. Dodge
- Mid-Iowa Community Action Agency, Ames
- North Iowa AIDS Project, Mason City
- Cedar AIDS Support System, Waterloo
- Linn County Aging and Disability Center, Cedar Rapids
- University of Iowa HIV Program, Iowa City
- ICARE, Iowa City
- Visiting Nurses Association, Dubuque
- The Project Quad Cities, Davenport

[13] National ADAP Monitoring Project Annual Report, Module 1. January 2012

Ryan White Part C Outpatient Primary Medical Care and Early Intervention Services

Part C of the Ryan White HIV/AIDS Treatment Extension Act of 2009 provides grants directly to service providers such as ambulatory medical clinics to support outpatient HIV early intervention services and ambulatory care. The Part C Early Intervention Services component of the Ryan White HIV/AIDS Program funds comprehensive primary healthcare in an outpatient setting for people living with HIV disease.

In FY 2011, Iowa's Part C clinics received approximately $1.6 million in Ryan White Part C funding and were able to provide the following services to over 1,200 patients:

- Risk-reduction counseling, antibody testing, medical evaluation, and clinical care;
- Antiretroviral therapies; protection against opportunistic infections; and ongoing medical, oral health, medical nutritional therapy, psychosocial, ophthalmology, and other care services for HIV-infected clients;
- Case management to ensure access to services and continuity of care for HIV-infected clients;
- Some support services such as linguistic services; and
- Addressing other health problems that occur frequently with HIV infection, including tuberculosis and substance abuse.

The following programs provide comprehensive primary healthcare for Iowans living with HIV disease:

- HIV Program/Virology Clinic, University of Iowa, Iowa City
- Primary Health Care Inc., Des Moines
- Siouxland Community Health Center, Sioux City
- Community Health Care Virology Center, Davenport
- HIV Clinic, University of Nebraska Medical Center, Omaha (Nebraska)

Ryan White Part F AIDS Education and Training Centers and Community

Part F provides funding for two different services in Iowa. First, the AIDS Education and Training Centers (AETC) Program of the Ryan White HIV/AIDS Program supports a network of 11 regional centers (and more than 130 local associated sites) that conduct targeted, multidisciplinary education and training programs for health-care providers treating people living with HIV/AIDS. The AETCs serve all 50 States, the District of Columbia, the Virgin Islands, Puerto Rico, and the 6 U.S. Pacific Jurisdictions. The AETC Program increases the number of healthcare providers who are effectively educated and motivated to counsel, diagnose, treat, and medically manage people with HIV disease, and to help prevent high-risk behaviors that lead to HIV transmission. Iowa is part of a regional consortium of AETC's called the Midwest AIDS Training and Education Center (MATEC) that serves the regional area shown at the right. Iowa has a state office at the University of Iowa Hospitals and Clinics in Iowa City, Iowa.

Housing Opportunities for People with AIDS (HOPWA)

HOPWA is a federal program funded by the United States Department of Housing and Urban Development (HUD). HOPWA provides housing assistance and related supportive services to address specific needs of low-income people living with HIV/AIDS. Services include tenant-based rental assistance, short-term rental, mortgage, and utility assistance, housing case management, housing placement services, and other supportive services for those living with HIV/AIDS.

In 2001, on behalf of the State of Iowa, the Iowa Finance Authority received competitive HOPWA funding. In 2004, the State of Iowa qualified instead for formula-based HOPWA funding, which is statutorily determined by HUD based on cumulative AIDS cases and area incidence. Since then, the annual formula funding has been lower than the previous competitive award. In recent years, HOPWA funding in Iowa has been approximately $400,000 annually, with modest increases each year as determined by the federal budget. The Iowa Finance Authority partners with five AIDS service organizations and housing agencies to offer services across the state.

HOPWA service providers in Iowa:

- Siouxland Community Health Center, Sioux City
- AIDS Project of Central Iowa, Des Moines
- Cedar AIDS Support System, Waterloo
- Iowa Center for AIDS Resources and Education (ICARE), Iowa City
- The Project of the Quad Cities, Davenport.

According to data reported by project sponsors, 135 households received housing subsidy assistance through HOPWA in 2011. Project sponsors are not required to maintain waiting lists and so it is difficult to accurately assess Iowa's housing need among PLWHA. Among the sponsors that kept a waiting list, however, 38 households were reported as having unmet needs.

Evaluation of Recent Goals and Initiatives

Iowa Counseling Testing and Referral (CTR) Sites
In 2011, the Iowa Department of Public Health (IDPH) funded 11 agencies to implement Counseling, Testing, and Referral (CTR) Services. IDPH supported HIV testing at two additional agencies via Memoranda of Agreement (i.e., no funding was provided). In addition, six state Disease Prevention Specialists conducted HIV testing as part of their delivery of partner services. All in all, 5,837 tests were administered, producing 29 new HIV-positive diagnoses (0.50% positivity rate).

A greater uniformity of service delivery among all IDPH-contracted CTR sites has been attained through the implementation of program standards, contractor reporting and feedback, counselor training, and data quality assurance. Performance measures were developed that require 80% of all tests to be administered to high-risk and disproportionately impacted populations, as defined by the CPG and described in the *Iowa's Comprehensive HIV Plan*. This has ensured the best use of resources and also facilitated the identification of more persons living with HIV who were previously unaware of their infections.

To reach the prioritized populations, providers expanded hours (billboard above advertised testing outside of a gay bar), provided testing through outreach at community venues, and implemented other culturally relevant strategies to reach people who wouldn't otherwise access HIV testing. The expansion of rapid testing to all IDPH-supported CTR sites also facilitated this goal. Below is an example of a Twitter message from one of Iowa's HIV testing sites showing the use of social media to reach high-risk persons.

In recent years, an increased emphasis was placed on testing MSM at CTR test sites. In 2009, 1,044 tests were administered to MSM.[14] This equates to 13% of all HIV tests delivered by the CTR test sites. In 2010, MSM accounted for 18% percent of the test recipients, although the total number tested decreased slightly to 1,018. Most recently, in 2011 a total of 1,126 tests were provided to MSM, with the percentage remaining level at 18. Although MSM are a priority population for all CTR services, there has been only a slight increase in the number of MSM who access STD testing at the same time as HIV testing (29% in 2009; 32% in 2010; and 33% in 2011). Contractors have also reported a decrease in the number of MSM getting tested for hepatitis C (8% in 2009; 3% in 2010; and 2% in 2011). The percent of MSM who receive hepatitis A/B immunizations has varied from year to year (10% in 2009; 14% in 2010; and 12% in 2011). These goals will remain important priorities for the future.

Emergency Room Testing

Offering HIV testing at important points of entry to healthcare is a goal of prevention and care programs. Beginning in 2008, HIV testing in an emergency room setting was piloted in Iowa. The bureau worked with one major hospital emergency room and encountered many barriers to routine rapid testing.

In part, barriers were related to a theoretical difference concerning the function of the Emergency Room. ER staff viewed HIV testing as a primary care function, unless it is warranted as part of the diagnostic work up. The program only succeeded when there was a dedicated person offering and performing the test. But having a dedicated staff person assigned to this task provided additional obstacles. These included the need for dedicated funding for the position and the limited number of hours that testing could be offered. Over the course of a year, 643 tests were performed, and two positives (0.3%) were found.

The other major barrier encountered was stigma and lack of awareness about risk among patients. Even when providers were willing to offer testing, patients were reported to decline testing because they didn't perceive themselves to be at risk for HIV. Patients often stated they didn't need a test because they were married, for example.

Given the barriers encountered in this initiative, a different approach is being taken to reach this population. A new collaboration is currently being formed with selected community health centers to pilot routine testing in higher-incidence areas of the state.

Policy Initiatives

The *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings,*[15]released by the CDC in 2006, called upon states to review testing laws and requirements. In accordance with these guidelines, opt-out testing for pregnant women in Iowa began July 1, 2007, after *Iowa Code 141A* was changed to include this provision. IDPH is currently in the process of evaluating the implementation of opt-out testing for pregnant women throughout the state.

[14] The category MSM, or men who have sex with men, is inclusive of MSM who also reported having injected drugs.
[15] http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm

Other policy barriers to prevention and care remain. The removal of the requirements for written consent for HIV testing of minors and for the parental notification of minors that test positive remains goals of the CPG and IDPH. Although a number of states have provisions that allow for notification of parents by providers when a minor tests positive for HIV, only Iowa requires it.[16] Iowa's law also requires that minors sign a statement confirming that they have been told of the law prior to testing. In July 2010, the Iowa Department of Public Health conducted a phone survey of 50 family practice clinics selected at random throughout Iowa to see how HIV testing of minors is handled. More than a fourth (28%) of the 50 clinics surveyed will not test minors for HIV. In those clinics, minors are referred elsewhere for testing. Of those who do test minors, only 64% (23) of clinics obtain written consent, and half indicated that they would not notify the minor's parents of a positive result. Written consent and parental notification are required by law. Overall, nearly 60% of providers who test minors are not following at least one aspect of current law for testing of minors.

In 2012, Iowa Code was amended to allow for better use of surveillance data for prevention and case management programs. Laboratory test results collected by the state may now be used to guide medical case managers and to help identify persons who have been lost to care. The department is working to update policies and case management consent forms to reflect this change.

Iowa is also one of 34 states and U.S territories with a statute that criminalizes exposing someone to HIV without their knowledge and consent (i.e., a disclosure law). The *National HIV/AIDS Strategy* calls for state legislatures to reconsider criminalization statutes that may act as barriers to public health prevention goals and that may interfere with public health strategies to reduce transmission of HIV/AIDS. In 2011 and 2012, advocates worked with Iowa legislators to introduce legislation to modernize the statute. The bills were not advanced out of committees, but CHAIN continues to educate Iowans and legislators on the need to address the law. It is expected that a new bill will be introduced in the 2013 session of the general assembly.

Social Determinants of Health

IDPH and the CPG have worked together to understand how social determinants of health (SDH) may contribute to the risks that specific populations may have in acquiring HIV and other STDs. Much of this investigation has been related to the disparities in rates of diagnoses of HIV, chlamydia, and gonorrhea in blacks and other African-Americans in Iowa, but Hispanic/Latino populations also experience disparities in diagnoses of these diseases, albeit not to the same extent.

In 2009, to address disparities in diagnoses of HIV among black, non-Hispanic Iowans and among Hispanic Iowans, and to reflect the impact that social determinants of health have on these minority populations, the CPG chose to prioritize certain disproportionately impacted populations (i.e., those populations with proportionately higher rates of HIV diagnoses). The addition of disproportionately impacted populations to other behavioral risk groups allows for prevention providers to work with populations that may report relatively low-risk behaviors, yet, due to an array of social determinants, still have high rates of STDs and HIV.

[16] Institute of Medicine. 2010. HIV screening and access to care: Exploring barriers and facilitators to expanded HIV testing. Washington, DC: The National Academies Press.

As a result of the prioritization of these two disproportionately impacted populations, eight health education/risk reduction projects were funded in 2010 and 2011 to reach these populations. The projects included Community PROMISE, SiHLE, SISTA, and Sister to Sister. Together, these projects enrolled 212 persons in group- or individual-level programs and reached another 1,094 in outreach. In addition, the proportion of HIV tests among African Americans/blacks at IDPH-supported CTR sites increased from 18% in 2008 to 33% in 2011, and the proportion among Hispanics increased from 10% in 2008 to 15% in 2011.

In 2010, the CPG and IDPH staff requested capacity building assistance to broaden the understanding of the impact of SDH. The Academy for Education Development facilitated an interactive workshop/training to assist participants in identifying SDH specific to Iowa. Participants were provided with resources and options for obtaining data and information for identifying the SDH. They were lead through a process of identifying short- and long-term priorities for Iowa. All felt that the training enriched their understanding of SDH and this has been reflected in further CPG discussions and prioritization of program activities.

It is true that individual-level determinants, including high-risk behaviors such as unsafe sexual and drug-injecting practices, are major drivers of disease transmission and acquisition risk. However, it is also clear that the patterns and distribution of these infectious diseases in the population are further influenced by a dynamic interplay among the prevalence of the infectious agent, the effectiveness of preventive and control interventions, and a range of social and structural environmental factors.

Many of these conditions arise because of the circumstances in which people grow, live, work, socialize, and form relationships, and because of the systems put in place to deal with illness, all of which are, in turn, shaped by political, social, and economic forces.

-Dr. Kevin Fenton
Director of CDC's National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention

Finally, the IDPH is working on a project with CDC to geocode HIV diagnosis data and to overlay those data with data on SDH from the U.S. Census and other sources. Geocoding of newly diagnosed cases can help IDPH to determine if new HIV diagnoses are concentrated in specific geographic locations, and can also help to visualize the epidemic over time. IDPH could also determine the proximity of newly diagnosed cases to identify specific group characteristics that may contribute to HIV transmission. Findings can be shared with community partners providing prevention and testing services in those areas. In addition, geocoding of living cases can help visualize where those not in-care for their HIV infection are located and whether access to services may be an issue in those areas. Finally, linking geocoded surveillance data to census information can help to identify areas and populations of increasing prevalence for HIV/AIDS, not only by race and ethnicity, but also by factors like poverty levels, housing availability, and other factors known to affect health.

Service Integration
Iowa has worked to deliver integrated services as much as possible. State and local DPS have always offered integrated HIV and STD partner services. In 2010, DPS were trained on recognizing and responding to domestic violence as part of Project Connect: A Coordinated Public Health Initiative to Prevent Violence against Women, supported by the Department of Health and Human Services (HHS), Office on Women's Health (OWH).

HIV CTR sites are able to offer STD testing, hepatitis B and C testing, immunizations for hepatitis A and B, TB testing, and referrals for substance abuse and mental health evaluation, housing opportunities, or other support services to their clients. However, funding has limited the capacity of the IDPH and its local partners to offer hepatitis B testing at many CTR sites.

Ryan White Part C clinics have also expanded their testing and other prevention services. The Siouxland Community Health Center (SCHC) is an example of a one-stop shop for prevention and care services. Services include housing assistance, case management, HIV treatment, HIV and hepatitis C testing, outreach, support groups, and prevention programming. In 2012, prevention programs included *Choosing Life: Empowerment! Action! Results! (CLEAR)*, for HIV-positive clients. CLEAR is a client-centered program delivered one-on-one using cognitive behavioral techniques to change behavior. Core sessions facilitate the development of personal goals, an individualized prevention plan, and assertive behavior and communication. The intervention provides clients with the skills necessary to be able to make healthy choices for their lives. SCHC also offers CLEAR to high-risk, HIV-negative MSM as part of the CDC-funded project for MSM with the AIDS Project of Central Iowa.

Partner Services (PS)
In 2011, state and local DPS interviewed over 5,500 persons who had been diagnosed with HIV or other reportable STDs. In total, 33% of chlamydia cases, 52% of syphilis cases, and 96% of gonorrhea cases were interviewed. Due to the high number of chlamydia cases (nearly 11,000 in 2011), interviews are limited to priority cases in most areas of the state. Early syphilis cases are fairly rare in Iowa, and late cases are generally not interviewed.

In 2011, 120 persons were diagnosed with HIV. Of those, 116 (97%) were offered partner services, and 107 were interviewed. These interviews elicited names of 219 partners. Of these, 188 were found and notified, 87 were tested, and 8 new positives were identified (9% positivity among those tested).

A vacancy in the STD Program manager position delayed a major partner services initiative. The implementation of Internet Partner Services is now underway. Internet-based Partner Services (IPS) is an investigative and case management tool that utilizes Internet-acquired locating information in the process of investigating and notifying the sex and drug-use partners of individuals who have been diagnosed with a laboratory confirmed infection. Traditionally, the most effective partner services interventions and notifications have been through face-to-face interactions. However, as electronic technologies, online venues, and other communication tools used to find sex partners have grown in popularity, it is necessary to use these same technologies, venues, and tools to deliver partner services. Policies and protocols have been developed and approved, and training of state and local disease prevention specialists occurred in August 2012.

Health Education/Risk Reduction (HE/RR)
In 2011, IDPH also funded 22 health education/risk reduction prevention interventions at nine different agencies. Within these programs, 2,681 individuals participated in at least one session of a group- or individual-level intervention. Agencies logged 8,410 targeted outreach contacts. Interventions included: Mpowerment; Community PROMISE (multiple populations targeted); CLEAR; Healthy Relationships; Project SMART; RESPECT; Reach One, Teach One; and VOICES/VOCES.

Project HIM was officially launched in March 2012 when about 200 people, mostly MSM, crammed into Lime Lounge in Des Moines' East Village to hear about the exciting new program and website. In June, Project HIM reached several thousand MSM through outreach during Pride. In the first year of testing, Project HIM tested 268 MSM, with a positivity rate of 1.5%. To date, 15 street team members have been recruited and trained to spread the word about Project HIM, including HIV testing, Project HIM model videos and the importance of sexual health in the community. Currently, four Project HIM model videos that showcase real guys from the community sharing their stories of positive change for HIV testing have been released. The videos boast an average view count of approximately 800 per video.

As previously stated, the IDPH-funded HE/RR projects were prematurely discontinued at the end of 2011. As a result only two agencies (three interventions) are being funded through a year-long contract (2012).

Capacity Building and Training
The IDPH HIV Prevention and Care programs have a long history of providing capacity building assistance and training for providers. In 2011, multiple evidence-based intervention trainings were held including CLEAR and SiLHE. The Fundamentals of HIV Prevention Counseling is also offered on a quarterly basis and is required of all CTR counselors. Many case managers and prevention specialists were cross-trained in these curricula. The inaugural class of the Medical Case Manager Certification Program was implemented in 2012. Iowa Part B staff worked with Diverse Management Solutions to develop the program and will provide ongoing training and support for the program.

Iowa has a long history of offering statewide conferences and capacity building opportunities for HIV prevention and care providers and Iowans. In 2010, IDPH held its 11th HIV, STD, and Hepatitis Conference, in conjunction with the Iowa Department of Education and MATEC. It was entitled *2010 - A New Decade: A Call for Change,* and it focused on the recently released *National HIV/AIDS Strategy*. In 2011, MATEC and the University of Iowa held its conference entitled, HIV 2011: An Interdisciplinary Conference. Speakers included Ron Valdiserri, Director, Office of HIV/AIDS and

Infectious Disease Policy, U.S. Department of Health and Human Services; and Keith Henry, MD, Director of HIV Research at Hennepin County Medical Center. Recently, IDPH and MATEC had alternated years to ensure that a statewide conference was offered each year. With the loss of federal HIV prevention funding for IDPH, no conference was held in 2012.

Reaching People living with HIV/AIDS (PLWHA) Who Are Not in Care

Part B staff works with the HIV partner services staff to find persons who were never linked to care or who initiated care but then stopped receiving services at a later time. A Retention-in-Care Initiative is in development at IDPH to formalize policies, procedures, and data collection tools for the effort.

DPS routinely work with HIV-positive individuals who are newly diagnosed or new to the state as part of the partner services program. Linkage to care and linkage to case managers and other support services are important aspects of their partner service delivery. Data from the HIV surveillance program indicate that 97% of persons living with HIV in Iowa were initially linked to care (as measured by the processing of a viral load or CD4+ cell count). Part B providers also work with DPS to find individuals who have left care to locate and re-engage them in care. The re-engagement process is an ideal time to revisit partner service needs.

A data import tool has been created to link the HIV case surveillance (i.e., eHARS) and Ryan White client-level data systems to ensure complete and seamless data for assessing unmet need for HIV primary medical care. It is currently in the validation phase and proper legal measures are being taken to ensure the confidentiality of these data is maintained when the import is complete. This linkage will provide better data to case managers to assess who is in care and who is at risk of being lost to care. They will also help medical case managers assess adherence to medications.

In early 2012, collaboration occurred in central Iowa between a Part B and a Part C provider to re-engage the agencies' clients/patients who were not in care. The IDPH has served as a consultant to this process and will be actively involved in the surveillance and program monitoring.

The Health Resources and Services Administration recently awarded funding to increase access to HIV treatment and care. Siouxland Community Health Center and the University of Iowa Hospitals and Clinics are local grantees. The goal of this funding is to increase primary medical care PLWHA who are new to care, previously diagnosed PLWHA who have never been in care, and PLWHA who are returning to care after more than a 12-month absence. Objectives of the funding include the following:

- To enhance systems to identify, link, re-engage, and retain PLWHA in care;
- To hire additional HIV primary medical care providers;
- To expand service hours;
- To expand outreach and HIV testing activities for high risk populations; and
- To expand support services to facilitate HIV primary care.

Barriers to Access

The Iowa HIV Anti-Stigma Campaign launched on December 1, 2009. The campaign included print, online, and television media spots with the following action statements: "HIV won't stop me from _____." Local celebrities and other activists were filmed or shown completing the action statement. The campaign ran through June 2010.

In addition, several World AIDS Day events were held throughout the state, including flash mobs in Des Moines and Sioux City and a scavenger hunt in Waterloo. All events focused on HIV-related stigma. The campaign's third tier will include more community awareness events, similar to those held on World AIDS Day, and a push to get funding and implement the Global Network of HIV-positive Persons (GNP+) HIV Stigma Index. The index has been implemented in over 20 countries around the world, but not in the U.S. Iowa could potentially be a pilot site for the project if funding can be secured.

Communication, Coordination, and Collaboration among Programs for PLWHA
Statewide and local efforts around Iowa have seen recent success in streamlining and coordinating of services for PLWHA while preventing duplication of services and efforts in the same geographical areas. Examples include:

- In 2012, two Ryan White Part B (care) contractors received HIV prevention funds to provide CTR services and evidence-based prevention interventions targeting HIV-positive persons and men who have sex with men.

- Integrated prevention and care planning occurs through the Community Planning Group. The decision to integrate the planning requirements of CDC (Jurisdictional HIV Prevention Plan) and HRSA (Statewide Coordinated Statement of Need and Comprehensive Care Plan) into one fully integrated plan is an example of the state's commitment to integrated planning and service delivery.

- Ryan White Part B, Part C, and MATEC have held annual, collaborative meetings since 2006. The purpose of the meetings is to provide an opportunity for MATEC and the leadership of Ryan White Parts B and C to ensure high quality, non-duplicative services through information sharing, coordination, and collaboration. The full-day meetings have included time for Part B and Part C staffs to break out and discuss recent changes, updates, successes, and challenges. Discussions of the Iowa Quality Management Plan and the development of statewide quality measures have been facilitated by these meetings. In 2011 the National HIV/AIDS Strategy and its potential impact at the state level was presented, as was Iowa's HIV Anti-Stigma campaign and its implementation in Iowa and Nebraska.

- Cedar AIDS Support System (CASS), a Ryan White Part B provider in Waterloo, is a member of the Community Group on HIV and AIDS in Black Hawk County. The group is composed of CASS case managers; representatives from Black Hawk County Health Department, Allen Women's Health Center, and Cedar Valley Hospice, as well as clients and other interested parties. Meetings are held quarterly. The goal is to enhance the education and outreach for HIV and AIDS through information sharing and education.

- Founded in December of 2010, the Sexual Health Alliance of Linn & Johnson Counties is composed of community members, staff from organizations such as Planned Parenthood, IDPH, Johnson County Health Department and Linn County Health Department, and advocates. The Sexual Health Alliance is a comprehensive coalition dedicated to the sexual health of their communities. Goals include making people in the community aware of local resources available such as disease testing. They also hope to lessen the stigma around testing and sexual health. They have a Facebook page, and are present at local gay pride events, condom crawls, and even farmer's markets.

Sexual Health Alliance
Of Linn & Johnson Counties

Quality Assurance

Iowa's case management standards are in the process of being revised and updated to reflect new service definitions from HRSA, including the requirements of medical case management and the differentiation between medical and non-medical case management. The process will be completed and the revised standards will be released later in 2012.

The Ryan White Part B Program's Client Services Coordinator at IDPH conducts monthly monitoring calls with Part B providers to discuss topics relevant to quality case management services and to provide technical assistance and support, as needed.

The ADAP is currently in the process of developing policies and procedures for the program to ensure that resources are used most efficiently. The new policies and procedures manual will be released in 2012.

SECTION 2. STATEMENT OF NEED FOR PREVENTION AND CARE IN IOWA

Opportunities, threats, barriers, gaps, and projected future changes are outlined in the following section. The data and information provided in this Statewide Coordinated Statement of Need was used by the Iowa Plan Development Committee to identify priority goal areas to improve the future of HIV prevention and care in Iowa.

Overview of Opportunities and Threats

The National HIV/AIDS Strategy
The National HIV/AIDS Strategy was a welcome guidance. In fact, the push to develop a national plan was initiated in Iowa and New Hampshire. During the 2007 – 2008 presidential campaign season, national and local advocates used a strategy called "bird dogging." Advocates took a coordinated approach to attend as many campaign speeches and events as possible in all areas of the state. The goal was to ask each candidate whether he or she would agree to the development and implementation of a national HIV strategy. As the issue came up frequently, both in Iowa and then in subsequent states, candidates became better prepared to respond to the question and most developed a formal position on the issue. For many in the state, the strategy represented hope for a coordinated national response, a renewed public interest in HIV issues, and an allocation of the necessary resources to bring about change.

The National HIV/AIDS Strategy was released in 2010 and is now in the implementation process. When developing Iowa's Comprehensive HIV Plan, the Plan Development Committee gave great consideration to the goals of the Strategy, and how we could contribute to their implementation as a state. Iowa has made great strides in targeting prevention efforts, increasing access to care and improving health outcomes, and addressing HIV-related disparities and health inequities. The goals of the National Strategy fit well with Iowa's efforts to date.

Treatment as Prevention (TasP)
Another major consideration of the Plan Development Committee was recent research concerning treatment as prevention. Evidence has been growing for years that people living with HIV who are on antiretroviral therapy not only experience lower viral loads and better health outcomes, but also benefit from a reduced likelihood of transmitting HIV to others. Two recent studies, *Partners in Prevention*[17] and *HIV Prevention Trials Network (HPTN) 052*[18], have shown that transmission of HIV is greatly reduced with antiretroviral therapy. *HPTN 052* is the first randomized study to support what many have previously suspected. With the high efficacy of treatment in preventing HIV transmission (more than 95% according to the *HPTN 052* trial), it has become even more clear that diagnosis, linkage, retention, and re-engagement in medical care, the activities that have been prioritized for many years, are important for prevention of HIV transmission as well. TasP offers one additional tool for HIV prevention in Iowa and elsewhere.

The Plan Development Committee carefully considered the risks and benefits to beginning treatment earlier in the course of the illness. Ideas were discussed to ensure patients fully understand the risks and benefits of treatment. Ethical considerations were discussed concerning whether treatment should be prescribed to individuals if a significant reason for doing so was to reduce their likelihood of infecting others. Discussion also involved continuing to monitor data on the risks, benefits, and effectiveness of early treatment. For example, a large clinical trial, called the *Strategic Timing of Antiretroviral Treatment (START),*[19] is being conducted in 30 countries and is expected to add more information to the discussion by 2015.

[17] http://depts.washington.edu/uwicrc/research/studies/pip_transmission.html
[18] http://www.hptn.org/research_studies/hptn052.asp
[19] http://www.niaid.nih.gov/volunteer/hivandinfectious/hivstudies/Pages/STARTStudy.aspx

However, another small study[20] conducted among 101 HIV-positive MSM showed that viral suppression in the blood does not always ensure viral suppression in seminal fluid. In fact, among 83 men with undetectable HIV in their blood, 25% had HIV in their semen. Especially in cases where HIV-positive MSM were also diagnosed with one or more STDs, ART treatment was not effective in suppressing HIV shedding in semen.

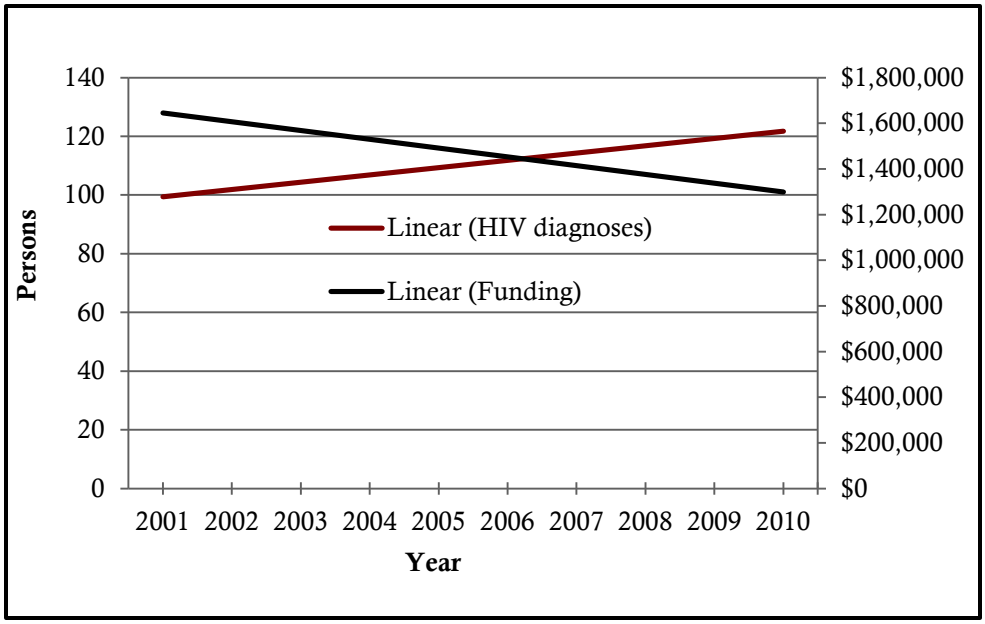
Despite similar concerns and discussions occurring around the country, at the end of March, the evidence was reviewed and new federally approved HIV treatment guidelines were issued. The new guidelines gave a "strong" recommendation of antiretroviral treatment for anyone with a CD4 count of 500 or below and a "moderate" recommendation for PLWHA with CD4 counts above 500.[21] This development changed the scope of the conversation among the planning committee because the question of whether or not to recommend earlier treatment had been answered at a broader level. It is now recommended that all persons, regardless of CD4+ cell count, should be on treatment. Concern remained among committee members, however, about how to implement these recommendations locally to ensure patients are adequately educated and supported in the decision-making process.

Funding

The aforementioned opportunities and tools to curb the HIV epidemic have been integrated into Iowa's Comprehensive HIV Plan. The question remains, however, as to whether or not the state can afford to take full advantage of these prospects in light of reduced funding. This question is not unique to Iowa, as many are asking this question in the United States and throughout the world.

At the time the National HIV/AIDS Strategy was released in July of 2010, Iowa was experiencing a pivotal moment in the implementation of prevention and care service delivery. HIV prevention funding was already tight after ten years of level funding. HIV diagnoses had been increasing at a rate of 3 per year for the last 10 years (Figure 4). The AIDS Drug Assistance Program had just eliminated its second waiting list in four years, but had not yet re-opened to new persons. At that time, applicants were being added to the list at a rate of 12 people per month.

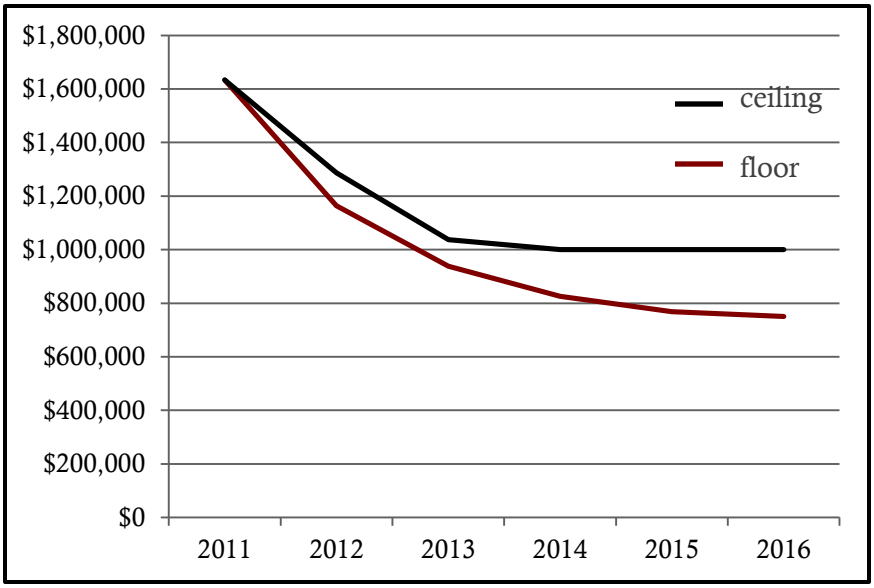
Figure 4 HIV Prevention Funding (adjusted for inflation) and New HIV Diagnoses



[20] JA Politch, KH Mayer, SL Welles, et al. Highly active antiretroviral therapy does not completely suppress HIV in semen of sexually active HIV-infected men who have sex with men. AIDS. March 23, 2012.

[21] http://www.aidsinfo.nih.gov/contentfiles/lvguidelines/aa_recommendations.pdf

Figure 5 Federal HIV Prevention Funding for Iowa (not adjusted for inflation)



In the summer of 2011, Iowa officials became aware of an intention of CDC to reduce the state's federal prevention funding by an amount ranging from 39% (if funded the ceiling level) to 55% (if funded the "floor" amount). The funding redistribution is a strategy implemented by the CDC to re-allocate funds to areas of the United States with higher HIV prevalence. Iowa's federal HIV prevention funding will be reduced over the course of 5 years and will ultimately limit Iowa's HIV prevention activities to a minimum level (Figure 5).

In 2012, IDPH funded only two contractors for the implementation of three behavioral interventions targeting HIV-positive persons and MSM. Prior to the funding reduction, the delivery of evidence-based behavioral interventions for HIV-positive and high-risk, HIV-negative persons was provided by nine community-based organizations (CBOs) and local public health departments. Funding categories were determined by the prioritization process, which was completed by the Community Planning Group in 2009. The interventions funded for high-risk negative persons included: Community PROMISE, MPowerment, Sister to Sister, SISTA, SiHLE, Respect, Reach One Teach One, Street SMART, and Voices/VOCES. Due to the significant reduction in funding for 2012, IDPH was no longer able to support the implementation of all of these interventions through the new Funding Opportunity Announcement (FOA).

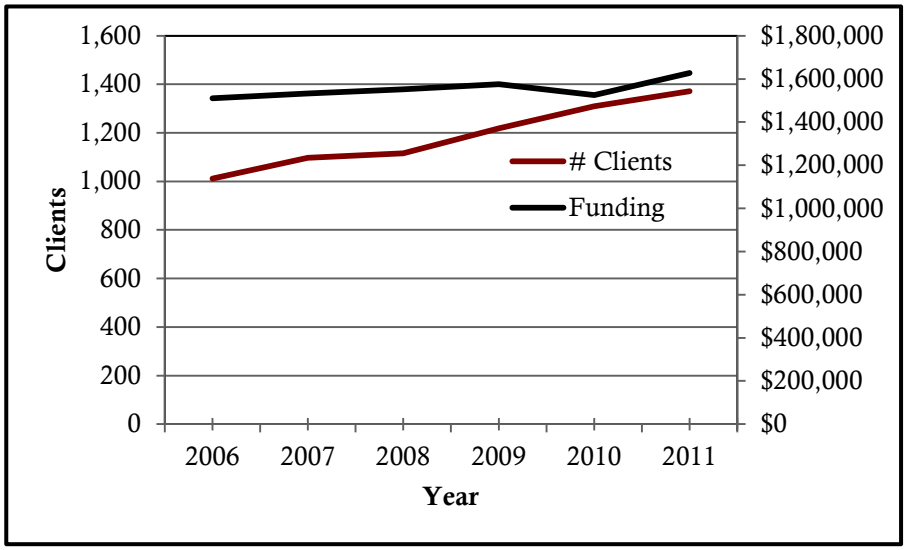
Although the state has a relatively low incidence of HIV, the number of new diagnoses has been increasing slowly but continuously since 2000, and there is concern about the impact the reduced funding will have on these numbers.

In addition, funding cuts to one state or local program can have significant impact on others. In Iowa, the integration of HIV prevention, HIV care, STD testing and treatment, viral hepatitis testing and immunizations, and other priorities is evident simply by viewing a program budget. Funding comes from multiple sources, employee salaries are broken down into several different program activities, and major initiatives are often sponsored by more than one grant. Therefore, the loss of prevention funding will have a significant impact not solely on the prevention program itself, but on the entire continuum of HIV and related services.

Even though funding for the Ryan White Part B Care program is expected to remain level at this time, re-authorization of the Ryan White CARE Act is forthcoming in 2013, and there are many unknowns due to the significant changes occurring in the area of healthcare reform.

For many years, Ryan White funding has remained level while the numbers of clients has increased (Figure 6). The graph below demonstrates how funding has not kept up with need among the Part C clinics in Iowa.

Figure 6 Ryan White Part C Funding



While the numbers have fluctuated slightly from year to year, new diagnoses and in-migration of persons previously diagnosed with HIV continue to contribute in equal measure to the pool of persons in need of HIV services and care in Iowa. Iowa recorded a total of 584 new HIV diagnoses from 2007 through 2011, an average of 117 diagnoses per year. During that same period, 537 previously diagnosed persons migrated into the state, an average of 107 persons per year. Over the five years, 1,121 additional HIV-infected persons, an average of 224 per year, were added to the state's registry (Table 7).

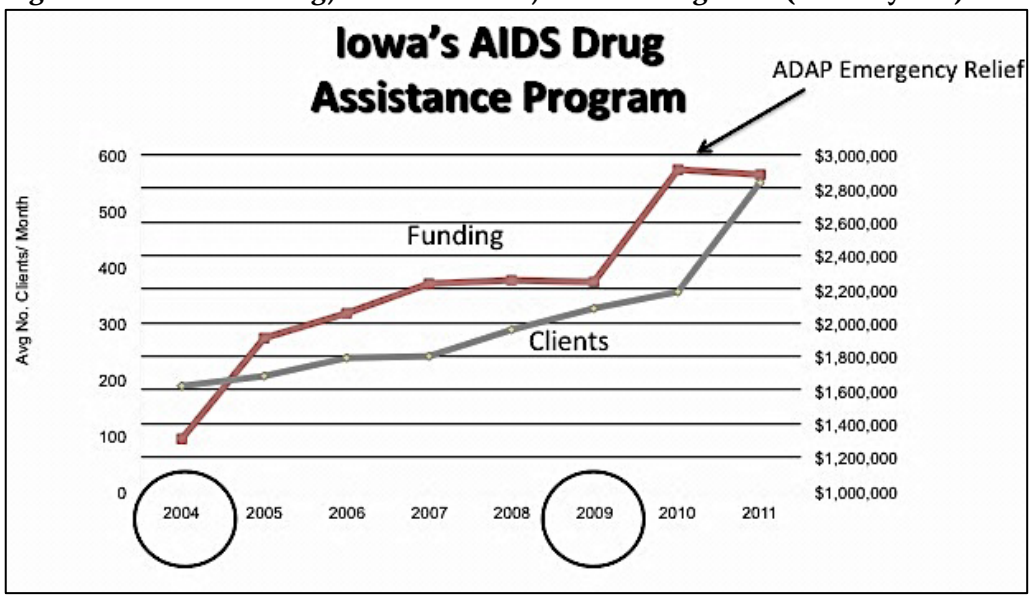
Persons diagnosed in other states who move to Iowa are not counted as Iowa's cases in case-based funding formulas for Ryan White services. The relatively large proportion of previously diagnosed persons who migrated to the state compared to those who are diagnosed while living in the state may be causing Iowa to receive insufficient funds for Ryan White services, including drug assistance.

Table 7 New Iowa HIV Diagnoses and In-migration of Persons Previously Diagnosed in Other States 2007 through 2011

	Year					5-Year Total	5-Year Average	5-Year %
	2007	2008	2009	2010	2011			
New Diagnoses	125	101	124	114	120	584	117	52%
Previously Diagnosed (New to Iowa)	124	94	119	108	92	537	107	48%
Totals	249	195	243	222	212	1121	224	100%

Iowa's AIDS Drug Assistance Program has faced two separate waiting list periods, the first from 2004 to 2005 and the second from 2009 to 2010. Increases in funding from state (2005) and federal (2010) sources allowed the program to reopen each time. The program is currently open to enrollees because of the continuing receipt of ADAP Emergency Relief Funding. As can be seen in Figure 7, however, client enrollment continues to outpace increases in state and federal funding.

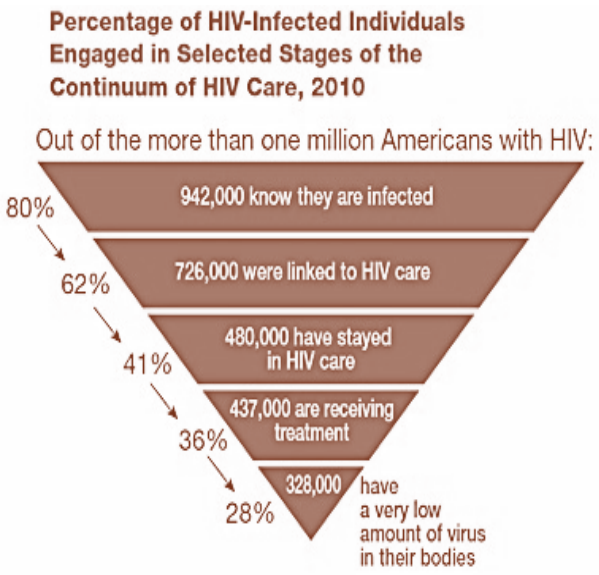
Figure 7 ADAP Funding, Clients Served, and Waiting Lists (circled years)



While there are many new tools and opportunities for care and prevention, including "treatment as prevention" or TasP, questions remain as to whether low-incidence states like Iowa will have the resources to contribute meaningfully to the goals of the *National HIV/AIDS Strategy* and/or benefit from the advancements in TasP.

HIV Cascade Model: A Gap Analysis Tool

Figure 8



Dr. Edward Gardner first introduced the concept of the treatment cascade in the March 2011 edition of *Clinical Infectious Diseases*[22]. Using available research, Gardner developed estimates of the number of PLWHA who were engaged along steps in a continuum of HIV care.

Gardner's treatment cascade was followed by an effort of the CDC to improve upon the estimates provided by Gardner's team using their own datasets. Both analyses showed that a significant number of people living with HIV in the United States do not progress through all stages of the cascade (Figure 8[23]).

In fact, according to Dr. Ronald Valdiserri, Director, Office of HIV/AIDS and Infectious Disease Policy, U.S. Department of Health and Human Services, the CDC's findings can be summarized as the following:

For every 100 individuals living with HIV in the United States, it is estimated that:

- 80 are aware of their HIV status.
- 62 have been linked to HIV care.
- 41 stay in HIV care.
- 36 get antiretroviral therapy (ART).
- 28 are able to adhere to their treatment and sustain undetectable viral loads.

Valdiserri states "In short, CDC estimated that only 28 percent of the more than 1 million individuals in the U.S. who are living with HIV/AIDS are getting the full benefits of the treatment they need to manage their disease and keep the virus under control. Put another way, nearly 3 out of 4 people living with HIV in the U.S. have failed to successfully navigate the treatment cascade."[24]

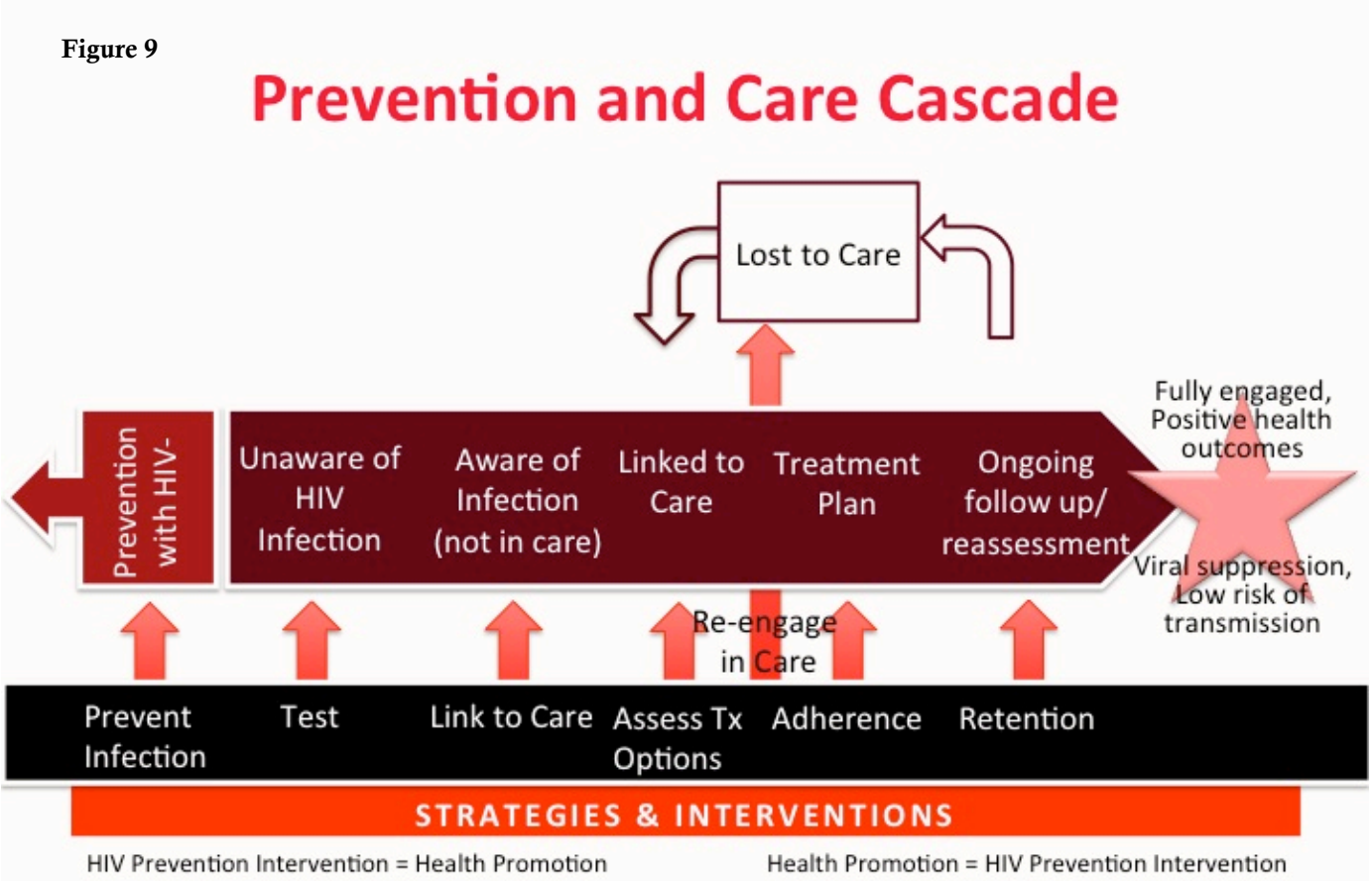
What does this mean for Iowa?
During Iowa's plan development process, with an awareness of the impact the loss of prevention dollars would have on the ability to maintain behavioral interventions, the cascade model was adopted to evaluate gaps where people are a) not successfully reached to prevent sero-conversion, b) not diagnosed, hence, remaining unaware of HIV infection, or c) disengaged from care and treatment, or d) otherwise unable to attain viral suppression.

By identifying the cascade steps where PLWHA fall out of care, Iowa planners can better determine where to target efforts and to which populations. Efforts can then be developed to strengthen

[22] Edward M. Gardner, Margaret P. McLees, John F. Steiner, Carlos del Rio, and William J. Burman. 2011. The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection. Clin Infect Dis. (2011) 52 (6): 793-800.
[23] http://www.cdc.gov/nchhstp/newsroom/docs/HIVFactSheets/TodaysEpidemic-508.pdf
[24] http://blog.aids.gov/2012/07/hivaids-treatment-cascade-helps-identify-gaps-in-care-retention.html

systems, enact policy, and develop programming to widen the gap at the bottom of the pyramid above. With this to guide planners, the following schema was developed:

Figure 9



In this model, strategies and interventions have been (or could be) implemented at each step of the cascade to encourage continued engagement and attainment of the end result of viral suppression. Iowa's numbers of people living with HIV who attain each step of the engagement process, then, provide opportunities to measure success and identify barriers that keep people from progressing along the continuum. The next section of this plan provides an analysis of these gaps and needs that are not currently being met at an optimal level.

A variety of sources were accessed to complete this analysis:

- HIV/AIDS Surveillance Data;
- The 2011 Consumer Needs Assessment;
- The 2010 Iowa GBT Men's Health Agenda;
- 2011 MSM Behavioral Surveillance Survey in Low Incidence States;
- 2011 Prevention and Care Program Reports;
- Presentations and data from MATEC-Iowa, HOPWA, Corrections, and Medicaid;
- 2009 Iowa HIV Prevention Provider Resource Surveys-Gap Analysis; and
- A variety of recent focus groups.

Assessing Iowa's Cascade: Prevention

Prevention Statement of Need

Prevention with persons who are HIV-negative is shown on the left in Figure 9. Iowa's goal has historically been to provide behavioral interventions to HIV-negative persons to keep them from moving through the rest of the cascade that would only apply to people who are infected with HIV.

Without behavioral prevention programming for high-risk HIV negative persons, a major gap exists at the beginning of the cascade that may result in additional people seroconverting in Iowa. To use the water analogy, the cascade may turn into a flood, and resources for testing, linkage, treatment, adherence and retention, which are already stretched, may not be sufficient to meet the added need caused by the reduction in prevention resources.

Even with the previous level of resources, which allowed for the implementation of behavioral interventions, prevention gaps remained. Funding was not available to support an optimal level of implementation of interventions to prevent future HIV infections in the state. This can be seen in the epidemiological data collected through the Iowa Department of Public Health. Iowa's number of HIV diagnoses had been increasing rather than decreasing. From 2000 to 2010, HIV diagnoses *increased* by an average of three persons each year. However, Iowa is only able to measure diagnoses, not true incidence, as some higher morbidity areas can. *Incidence* is a measure of the new infections that occurred in a specific area and time. Many of the people who are newly infected will not get diagnosed for many years. In particular, Iowa has a higher proportion of late testers than most states. The number of people who get diagnosed in a given year is affected by many factors not related to incidence, and trends in diagnoses may not reflect trends in incidence. In general, it is estimated that 20% of HIV-infected persons have not been diagnosed.[25] Nevertheless, the continuous increase in diagnoses over 10 years is an indication that true incidence may also be increasing in Iowa.

People Living with HIV/AIDS

People living with HIV are considered to be the highest priority population by the Centers for Disease Control and Prevention and the Iowa CPG. PLWHA have been a driving force in HIV prevention across the country – sharing their experiences, advocating for resources, and encouraging others to get tested. Most people who know they have HIV actively work to prevent transmitting the virus to others. Some seek prevention counseling services, participate in group prevention interventions, and utilize free condoms. As with all populations, barriers to prevention exist among people living with HIV, and it is important to seek understanding without judgment to best determine how to assist PLWHA in their efforts to avoid HIV transmission.

The 2011 Iowa Consumer Needs Assessment (CNA) provided basic prevention background information as well as behavioral surveillance information. Ryan White Part B and Part C providers mailed or distributed surveys to HIV-positive clients. Fifty-eight percent of the 378 respondents indicated they had been sexually active in the past year. A majority of participants reported use of condoms, monogamy, serosorting, and abstinence as behaviors they use that prevent HIV transmission.

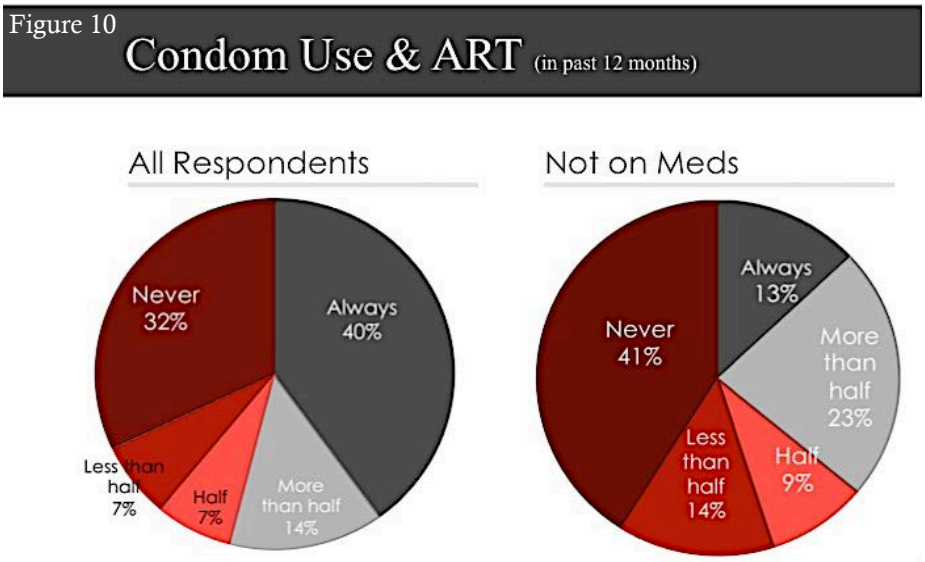
[25] http://www.cdc.gov/hiv/resources/factsheets/PDF/HIV_at_a_glance.pdf

Other key findings include:

- Less than half (44%) of respondents had engaged in one or more high-risk activities within the last year.
- Two percent reported that they had shared a needle or syringe with someone for either medical or recreational purposes.
- Twenty-eight percent reported that they had not used a condom every time they had sex with another HIV-positive person
- Twenty-one percent reported that they had not used a condom every time they had sex with someone who was HIV-negative or who was unsure about his or her HIV status.
- A high percentage, 88%, disclosed their HIV statuses to their last sexual partners.

Because it has been demonstrated that use of antiretroviral medications reduce the likelihood of infection, condom use among people who were taking medications was compared to condom use among all respondents. As shown in Figure 10, condom use was lower among people not taking HIV medications.

Figure 10



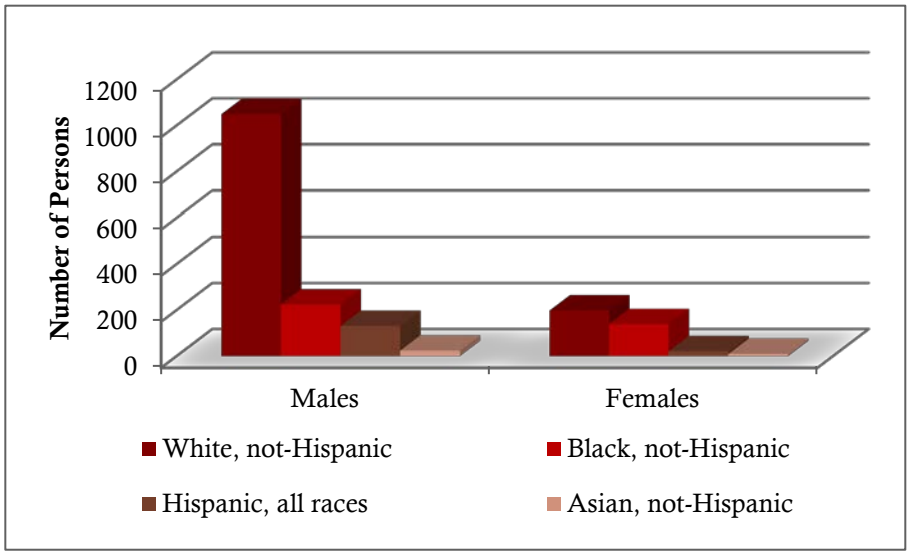
Most respondents received their first positive test in a hospital (24%), health clinic (22%), or at a physician's office (19%). Seventy percent of respondents reported that they had received information from a doctor, counselor, or case manager about how to lower their chances of transmitting HIV to others after receiving the results of their test. Fifty-four percent accessed prevention counseling services and 17% participated in a group-level intervention.

The data from the CNA demonstrates an ongoing need for HIV prevention services past the point of diagnosis. Due to reduced funding, however, the infrastructure to provide prevention services to PLWHA has been negatively affected.

Who Is Affected? Health Disparities & Disproportionate Impact

New diagnoses continue to affect men who have sex with men, African Americans/blacks, and Latino(a)s disproportionately.

Figure 11 Persons Living with HIV/AIDS by Race and Gender on Dec 31, 2010

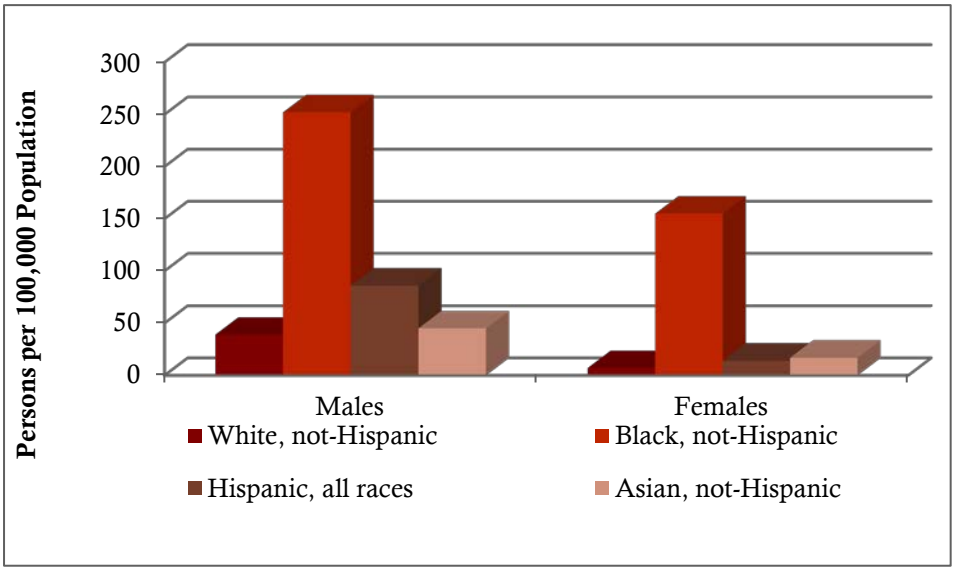


Although white, non-Hispanic males account for the largest number of persons living with HIV (Figure 11), black, non-Hispanic males and females are more severely impacted when the sizes of their populations in the state are taken into consideration.

Figure 12 shows the prevalence of HIV by race and ethnicity. Prevalence is calculated based on the number of persons per 100,000 population.

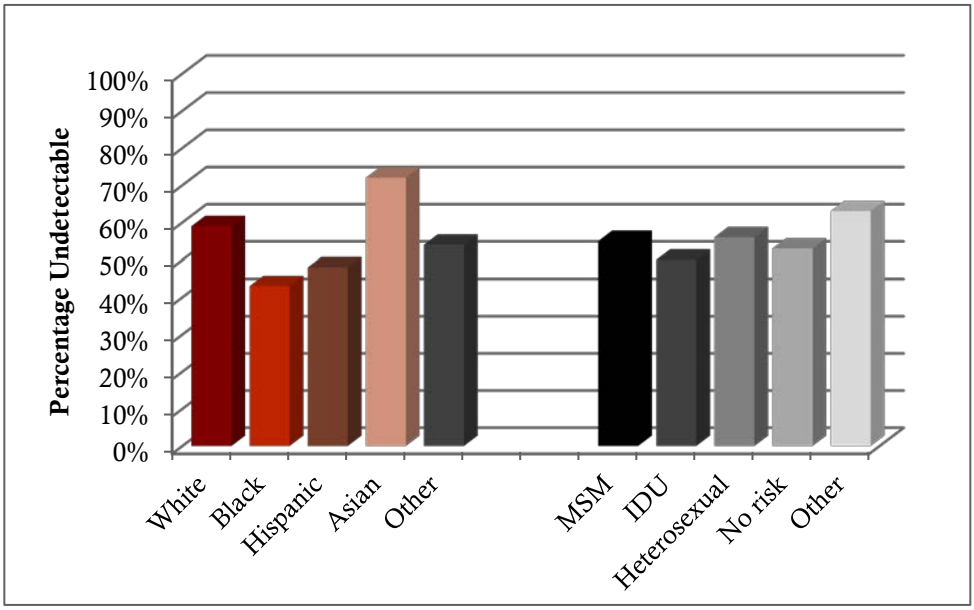
Figure 12 HIV Prevalence by Race and Ethnicity

In addition to risk behaviors, structural barriers contribute to the disproportionate impact of HIV on specific populations. These macro-level forces include discrimination; cultural norms; co-factors such as substance use and addiction; concurrency of sexual partners; rates of incarceration; community viral load; and residential segregation.



While African Americans/blacks and Latino(a)s experience disproportionate rates of HIV infection, they are also more likely to experience negative health outcomes from HIV infection. Once diagnosed, they are less likely than other racial and ethnic groups to achieve undetectable viral loads (Figure 13).

Figure 13 Viral Suppression by Race/Ethnicity and Risk Factor



African Americans/blacks

Twenty percent (5,951) of all IDPH-sponsored HIV tests from 2007 to 2010 were administered to African Americans/blacks. In 2011, this percentage increased to 33%. African Americans/blacks accounted for 22% (30) of new HIV diagnoses among sponsored agencies. In the same time period, African Americans/blacks accounted for 19% (86) of 462 new HIV diagnoses across the state during those same years. Considering African Americans/blacks make up only 2% of Iowa's population, these data demonstrate a strong disproportionate impact among this population.

African Americans/blacks were more likely than any other racial/ethnic group to report having sex without a condom in the last 12 months (71%). Non-MSM African American/black males were particularly at higher risk for unprotected sex. Seventy-four percent of non-MSM African American/Black males reported sex without a condom in the last 12 months, compared to 69% of non-MSM Hispanic males and 64% of non-MSM white males. African Americans/blacks also reported more previous STD diagnoses (21%) than their white (14%) or Hispanic/Latino (14%) counterparts.

Numerous factors contribute to the racial and ethnic disparities in HIV diagnoses among African Americans in Iowa. Recent national studies have shown that residential segregation, lower marriage rates, higher rates of incarceration, and higher rates of concurrency may contribute to population mixing patterns that promote higher HIV and STD rates among blacks.[26] In Iowa, Black, non-Hispanic persons experience rates of gonorrhea that are nearly 33 times higher than whites and more than 15 times higher than the state rate. African American/black Iowans are more likely to have been incarcerated than any other racial or ethnic group. In fact, in a July 2007 report called *Uneven Justice: State Rates of Incarceration by Race and Ethnicity*[27] published by The Sentencing Project, a national organization advocating for fair criminal justice reform, Iowa ranked first among states for

[26] Adaora A. Adimora and Victor J. Schoenbach. 2005. Social Context, Sexual Networks, and Racial Disparities in Rates of Sexually Transmitted Infections. JID 2005:191 (Suppl 1); S115-S122.
[27] http://www.sentencingproject.org/doc/publications/rd_stateratesofincbyraceandethnicity.pdf

disparate incarceration rates of African Americans/blacks. For every Caucasian incarcerated, 13.6 African-Americans/Blacks were incarcerated in Iowa. The national average black-to-white ratio was 5.6-to-1. Incarceration of African American/Black males reduces the ratio of males to females, destabilizes marriages, and increases the likelihood of concurrency among the partners of incarcerated men. Other social determinants among African-Americans may include poorer access to healthcare, education, and higher-paying occupations that promote mobility in socioeconomic status.

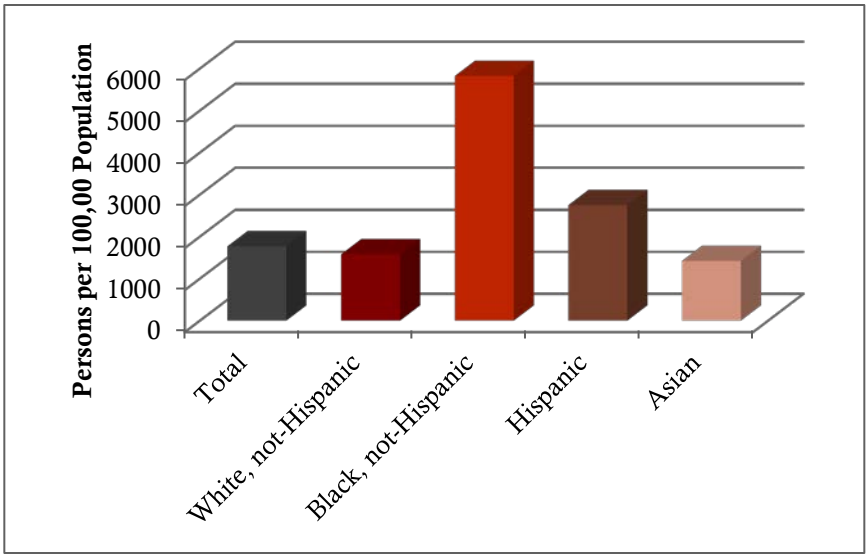
Hispanic/Latino(a)s

Between 2007 and 2010, 2,966 HIV tests were administered to Hispanic/Latino(a)s, accounting for only 10% of 30,255 total tests. In 2011, 15% (848) of tests were administered to Hispanic/Latino(a)s. Only 40% of those tested at sponsored agencies reported a previous HIV test, significantly less than African Americans/blacks (62%) and white, non-Hispanic persons (51%). Just over half of all Hispanic/Latino males and 43% of all Hispanic/Latina females (43%) tested were born outside of the United States. The most common risk for men is male-to-male sex. Many of these men are migrant workers with low economic status and low levels of education. Cultural mores, homophobia, and language barriers are social determinants that contribute to risk for HIV among Latino(a)s.

Men Who Have Sex with Men (MSM)

Men who have sex with men are the most impacted population in Iowa. Using an estimate that approximately 4% of adolescent and adult males have sex with other males, the prevalence of HIV among MSM in Iowa is nearly 1800 per 100,000 population, 30 times that of the general population. Among MSM, black, non-Hispanic males are the most impacted population in Iowa, having a prevalence that is more than 3.6 times that of white, non- Hispanic MSM (Figure 14).

Figure 14 HIV Prevalence among MSM by Race and Ethnicity



With a comparatively higher prevalence of HIV among Iowa's MSM, and a small population pool from which partner selection occurs, HIV is most frequently transmitted within this population in Iowa. Between 2007 and 2010, 4,060 MSM (13% of 30,255 tests) were tested at IDPH-supported CTR sites. In 2011, 17% of tests performed at these sites were among MSM, indicating a significant improvement in reaching this priority population.

Based on risk behavior data, MSM were significantly more likely to have had sex with someone who was HIV-positive than any other risk group. Twenty-one-percent (853) of all MSM tested at CTR contracted agencies reported having sex with an HIV-positive person. This compared to only 8% of all HRH and 5% of IDU. MSM were also more likely to have had sex with an anonymous partner within the last 12 months (38%), slightly higher than among heterosexual males (36%).

Of all risk groups, MSM were also the most likely to have had sex with someone they met on the Internet within the last 12 months (29%). Only 3 to 5% of members of all other risk groups reported the same behavior. This may, in part, be due to Iowa's rural landscape. Many MSM live in smaller rural communities and have reported feelings of isolation. The Internet is often the primary means to find partners for these men.

Other Populations at Risk: High-Risk Heterosexuals (HRH)
Between 2007 and 2010, 6,940 HRH were tested (23% of 30,255 tests) by IDPH-supported CTR sites. Most heterosexual individuals qualify as HRH because of STD diagnoses within the last 12 months (54%). In addition, HRH were more likely to report having sex without using a condom within the last 12 months than other risk groups (69%). This compared to 66% of IDU and 62% of the general population.

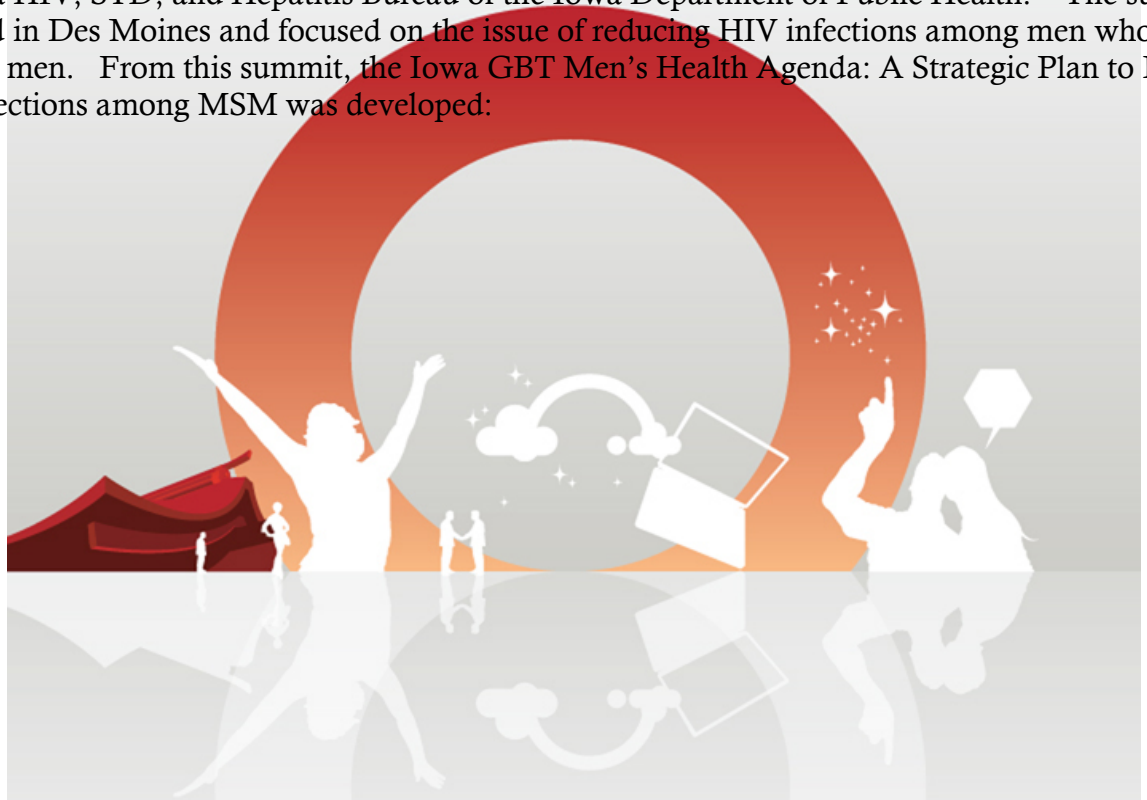
Other Populations at Risk: Injection Drug Users (IDU, including MSM/IDU)
Between 2007 and 2010, 4,173 IDU were tested (14% of 30,255 tests) by IDPH-supported CTR sites. Comparatively high percentages of IDU reported having sex while on drugs (78%), having sex without a condom within the last 12 months (66%), and having sex with an anonymous partner (33%). Also, IDU were more likely than any other risk group to disclose having exchanged sex for drugs, money, or other goods (21%). Only 13% of all HRH and 5% of MSM reported the same behavior.

Needs Assessment Data

In addition to the epidemiological and CTR data presented in the previous pages, Iowa has conducted a variety of needs assessments to further identify gaps in services and priorities for better addressing the epidemic.

Iowa GBT Men's Health Agenda

On June 2-3, 2009 more than 50 Iowans from Gay/Bisexual/Transgender (GBT) communities, including service providers and national colleagues, gathered to meet with select representatives from the Iowa HIV, STD, and Hepatitis Bureau of the Iowa Department of Public Health. The summit was held in Des Moines and focused on the issue of reducing HIV infections among men who have sex with men. From this summit, the Iowa GBT Men's Health Agenda: A Strategic Plan to Reduce HIV Infections among MSM was developed:



Iowa GBT Men's Health Agenda

Goal One: Develop a holistic approach to HIV prevention for the GBT community.

Ranked Objectives with Suggested Strategies

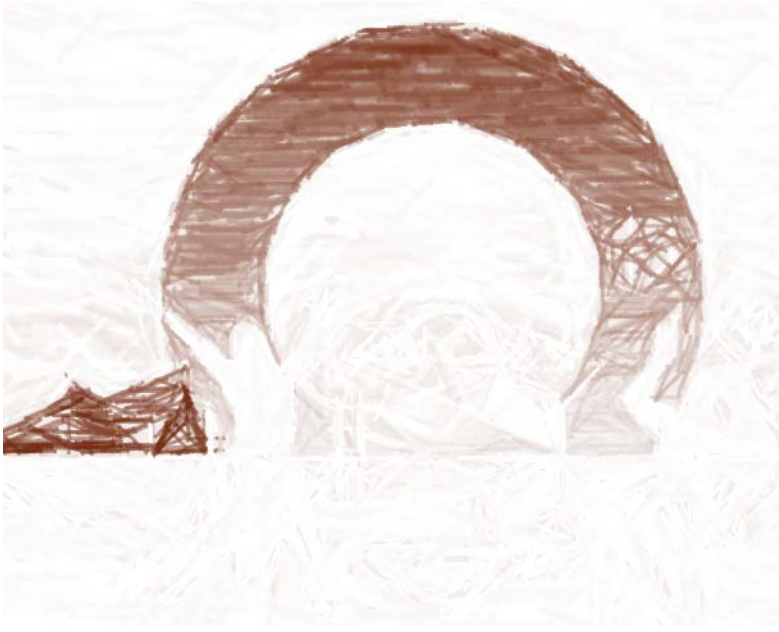
1. Develop a marketing campaign to address HIV among MSM.
    a. Focus on culturally competent and relevant messages.
    b. Conduct and use market research.
    c. Use flexible messaging specific to sub-populations (rural, age, status disclosure, cultural identity, etc.).
    d. Expand the message beyond HIV (anti-stigma, normalize gay relationships, self-worth, risk co-factors, other STDs, etc.).
    e. Use positive messages (visualize healthy vs. avoid the plague).
    f. Identify and utilize positive role models in marketing efforts.
2. Fund and adapt interventions designed to reach MSM who utilize the internet as a mechanism to meet sexual partners.
    a. Investigate and implement successful internet interventions and adaptations.
    b. Use internet tools to encourage a reduction in anonymous/multiple partners.
3. Utilize prevention strategies that focus on overall wellness.

a. Investigate GBT-focused alcohol abuse prevention programming.
b. Re-vamp bar outreach to address broader wellness issues.
c. Plan and implement a gay men's health week.
d. Expand and create new "GBT space."
e. Tie wellness theme into HIV prevention marketing.
f. Celebrate our lives as healthy sexual persons.
g. Increase access to mental health and substance abuse services.
h. Increase access to sterile syringes.
i. Support insurance reform and affordable healthcare initiatives.

Goal Two: Ensure availability of GBT culturally-responsive services.

Ranked Objectives with Suggested Strategies

1. Encourage and support GBT cultural effectiveness efforts targeted to the broader community.
    a. Build an educational network and speaker's bureau for healthcare, mental health, substance abuse, and other providers.
    b. Use incentives to encourage and reward providers who provide culturally effective services (public acknowledgment, ally awards, etc.).
    c. Develop community leaders through training, mentoring, and recognition
    d. Take an active role in framing and responding to the wider community conversation about gay marriage, sex, and relationships.
    e. Support visibility of GBT lives and role models.
    f. Work toward GBT-inclusive curricula in schools.
2. Provide funded agencies educational opportunities to enhance cultural competency skills.
    a. Provide capacity-building assistance and training.
    b. Incorporate MSM's wellness and cultural effectiveness issues into Iowa's HIV conference agendas.
    c. Conduct/support community-identification processes with communities not currently being reached (faith-based, rural, non-identified, etc.).
    d. Offer training in selecting and adapting culturally appropriate HIV prevention interventions.
3. Monitor the cultural accountability of funded ASOs and provide technical assistance to improve the performance of agencies in the areas of cultural effectiveness.
    a. Identify needs related to cultural competency.
    b. Encourage collaboration with non-traditional partners.
    c. Develop cultural effectiveness goals with funded agencies.
    d. Establish a monitoring/reporting system for cultural accountability.



Goal Three: Reach out to better meet GBT community needs.

Ranked Objectives with Suggested Strategies

1. Refocus and remarket HIV testing to increase the number of MSM accessing state-funded testing.
    a. Explore feasibility of an outreach van.
    b. Evaluate and build capacity for social network strategy.
    c. Increase *outreach* testing.
    d. Increase use of rapid testing.
    e. Advocate for opt-out HIV testing.
    f. Add MSM to the list of populations as defined by Iowa legislation for whom HIV testing must be offered in healthcare situations.
    g. Normalize routine testing (every 6 months) and preventative care.
    h. Establish culturally appropriate testing for MSM of color.
2. Increase community involvement in HIV prevention service delivery and expand reach of services.
    a. Require that grant applicants involve target populations in service delivery, program design, and evaluation.
    b. Encourage use of peers in programming and provide additional support such as an email list group for peer advocates.
    c. Identify peer advocates/strategies to reach non-identified MSM.
    d. Increase use of community-level interventions.
    e. Investigate interventions for rural Iowa.
    f. Research Latino-MSM directed interventions.
    g. Leverage the internet and other technology.
    h. Explore and support development of homegrown interventions.
    i. Establish broad partnerships; reach outside of the HIV community.
3. Assist in the development of an advocacy platform and support the advocacy of current policy groups working on issues of significance to our community.
    a. Increase resources for HIV prevention.
    b. Assist in efforts that address the backlash to gay marriage.
    c. Eliminate parental notification law for HIV testing.
    d. Consider the following potential issues as part of an advocacy platform: housing shortage, AIDS Drug Assistance Program, criminal exposure law.

Goal Four: Maintain flexibility and adaptability in our HIV strategies and efforts.

Ranked Objectives with Suggested Strategies

1. Conduct periodic market research to remain fresh in the approaches used to reach the GBT community.
    a. Encourage creativity.
    b. Adapt edgy, entertainment approaches.
    c. Monitor ongoing research into promising biomedical approaches to prevention that may be useful to MSM (post-exposure prophylaxis, pre-exposure prophylaxis, rectal microbicides, etc.).
2. Utilize technology as it evolves to maintain effectiveness of HIV prevention.
    a. Explore the use of technology to perpetuate prevention messages that spread via word-of-mouth (Viral outreach, social marketing).
    b. Investigate the implementation of internet-based partner services.
    c. Partner with internet service providers, such as Manhunt, to deliver prevention messages and advertise services.
3. Strengthen alliances that will allow for optimal prevention planning and delivery
    a. Look beyond HIV-specific alliances: School boards, Insurance companies, faith communities, mental health providers, etc.
    b. Increase GBT representation on Iowa's HIV Community Planning Group.

c. Create/increase distribution of a prevention roadmap and shared language to increase accessibility for people outside of the "HIV community" who wish to become involved.
d. Promote and support GBT scholarship programs.
e. Advocate for reduced bureaucratic barriers to prevention.
f. Build the capacity of all Iowa communities to respond to HIV.

The MSM Summit Steering Committee recommended that the Iowa HIV Community Planning Group adopt the strategic plan for addressing HIV among MSM in Iowa, and it was unanimously approved. The steering committee also recommended that the group be adopted as an ad hoc advisory committee to the CPG. From this recommendation, the Taking A Stand Committee (TASC) was formed to provide a strong connection between the CPG and the GBT community, to assist with the implementation of the strategic plan, and to provide guidance and insight on issues related to MSM health. To further provide direction, based on limited funding and resources, the strategic plan objectives were ranked according to community priorities and the following top three objectives were offered for guiding the distribution of limited resources:

1. Develop a social marketing campaign.
2. Use technology for prevention/online interventions.
3. Refocus and remarket HIV testing.

Key Findings from MSM Behavioral Surveillance Survey in Low Incidence States: Iowa Data
TASC members and Iowa's directly funded CDC project for MSM, Project HIM (Healthy Iowa Men) was fortunate to be included in MSM behavioral surveillance surveys of low incidence states through a collaboration with Emory University in 2011-2012.

Recruitment of Iowa MSM occurred through targeted Facebook ads, Google ads and MSM web sites. Eligibility criteria included that the survey respondent be male or transgender, over age 18, and reported anal sex within the past 12 months. A total of 380 Iowa MSM provided complete survey responses. Race and ethnicity of the respondents was as follows: White (90%), Black (2%), Asian (2%), and Hispanic/Latino (2%). Over half the sample, 56%, was below age 35.

Younger respondents indicated they had not regularly accessed HIV testing. In fact, 42% of MSM aged 18 to 24 years (n=108) had never been tested for HIV compared to 15% or less for other age groups. Regardless of age group, most respondents were not testing for STDs regularly; only 34% reported STD testing in the last 12 months. In addition, 38% had not received hepatitis A/B vaccinations.

Intermittent condom use was reported for varying situations. For example, 42% reported only protected sex with casual partners (n=42), whereas 27% reported only protected sex with main partners.

Of those reporting unprotected sex, knowledge of the HIV status of partners had little impact on condom use. About half reported unprotected insertive or receptive anal sex with an HIV-negative casual partner. Similarly, for MSM who reported casual sex with a partner of unknown status, about half reported unprotected insertive or receptive anal sex.

Drug use was seldom reported. Only 7% of respondents reported ever injecting drugs and less than 20% reported sex when high within the past 12 months.

Access to free condoms was reported among approximately half of the respondents, and this percentage did not vary by rural or urban residence.

Disclosure of sexual orientation to one's physician was only confirmed by 46% of participants. Of those who shared their sexual orientation, only 27% of their medical providers recommended an HIV test. Of the survey respondents who indicated they had a "regular doctor," 36% of the physicians asked if the patient was MSM. Of those MSM who were asked, 60% answered affirmatively.

Respondents gave an indication of places where they interact with one another. Most were not frequently going to the bars; 77% go to gay bars/dance clubs less than once a month or never. Fifty-seven percent of men in rural areas stated they travelled to larger cities to socialize with other gay and bi men a few times a year or more. In addition, over 60% went online to meet sex partners within the past year. Common websites/apps included Facebook, Craigslist, Manhunt, and Adam4Adam. However, seventy percent of respondents "often" or "always" use these sites for purposes other than to look for sex.

2009 Iowa HIV Prevention Provider Resource Surveys – Gap Analysis

The last Prevention Provider Resource Survey was conducted by the Needs Assessment/Community Resources Committee of the Iowa HIV/AIDS Community Planning Group in 2009. The surveys were part of the overall needs assessment and gap analysis completed for the CPG. They are useful for determining the level of services provided in different areas of the state to the priority populations. The information was used to identify gaps for future services and interventions.

Surveys were distributed to agencies most likely to provide counseling, testing, and prevention services for HIV/STDs, especially community-based organizations and agencies serving minority populations. Seventy-six agencies were sent a link to the survey on Survey Monkey. Fifty-two agencies responded, for a response rate of 68%. The types of agencies responding included:

- 14 (29%) family planning agencies;
- 10 (21%) city/county health departments;
- 11 (23%) community-based organizations;
- 8 (17%) community health centers;
- 2 (4%) correctional facilities;
- 2 (4%) free medical clinics;
- 5 agencies answered "Other," including a not-for-profit agency, a university health center, a private medical clinic, an HIV medical clinic, and a federal vocational training program

Forty-seven respondents said they provided HIV prevention services, including 43 that provided HIV testing. Nineteen of those provided rapid HIV tests. A majority indicated they provided basic information (93%), condom distribution (88%), and risk-reduction counseling (86%). When asked about the populations they served, the following responses were given:

- General population – 36 (89%)
- Persons infected with STDs other than HIV – 35 (80%)
- Young adults (13 to 24 years of age) – 35 (80%)
- Heterosexuals having sex with someone at risk for or infected with HIV – 29 (66%)

- Men who have sex with men – 27 (61%)
- Substance abusers – 27 (61%)

The challenges in providing service were:

- Insufficient funding – 26 (72%)
- Insufficient staffing – 18 (50%)
- Training for staff – 12 (33%)
- Recruitment and retention of intervention populations – 9 (28%)
- Small size of the target population – 9 (28%)

Finally, respondents were asked, "What are your intervention/skills area training needs?"

- Social marketing – 21 (54%)
- Using the Internet as an effective intervention tool – 18 (46%)
- Risk reduction – behavior change – 17 (44%)
- Implementing scientifically proven/evidence-based interventions – 17 (44%)
- Providing and tracking appropriate referrals – 15 (39%)

Of note in this survey, the populations at the highest risk for HIV infection are the least served populations (MSM, substance abusers), and the most effective programming (evidence-based interventions) are the least likely to be utilized. Needs for funding, training, and staff retention and recruitment were all cited as the primary barriers to delivering quality prevention services.

When reviewing the Provider Resources Survey, the Taking a Stand Committee decided to conduct an extended survey to assess provider resources to serve MSM. Surveys were emailed to 112 agencies, and 40 completed surveys were returned (36%).

About half (51%) of respondents stated they serve MSM; however, only 37% of respondents target services to MSM. Twenty-eight percent of agencies indicated they had staff who worked directly with the MSM community. Forty percent did not recruit MSM for program activities, and 33% did no advertising of services to MSM.

When asked about barriers, 66% indicated that the stigma of accessing services was significant. Other significant barriers included lack of transportation to service providers, lack of tailored programming to rural MSM, and lack of buy-in from the community. Agencies reported needing assistance with recruiting MSM to participate in programs, conducting outreach with MSM, using technology to reach MSM, and training staff to be culturally competent in working with this community.

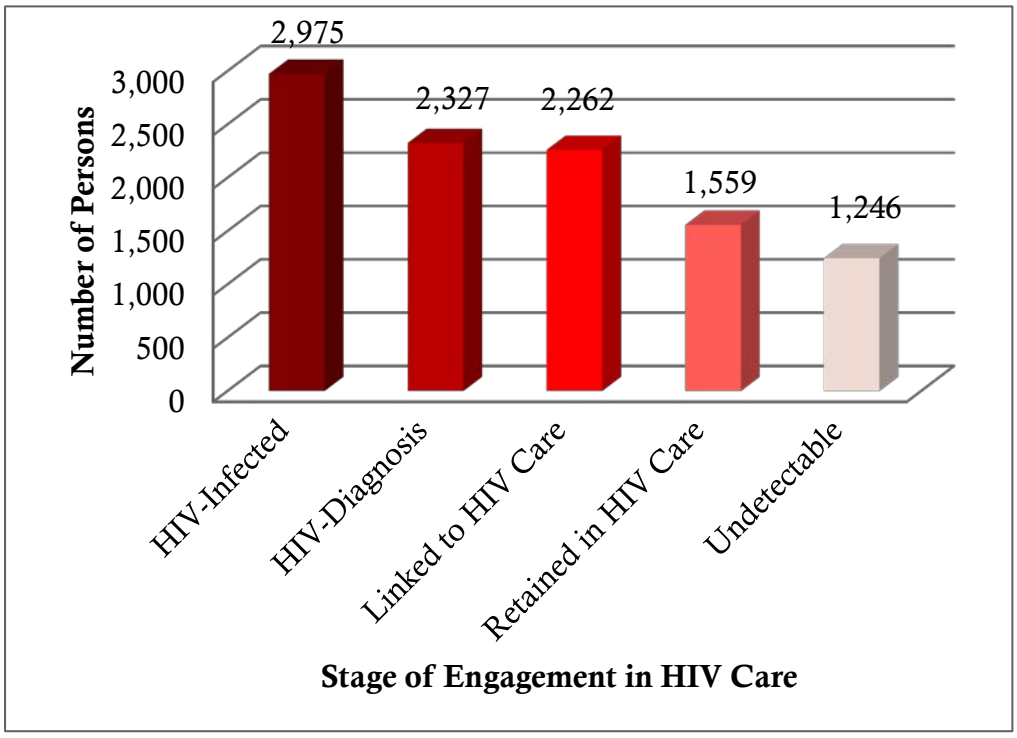
Based on the MSM Provider Resources Survey, TASC made the following recommendations:

- Increase the percentage of MSM who access HIV testing services;
- Increase the number of agencies in Iowa who work with the MSM community by providing technical assistance and capacity building opportunities in cultural competency; and
- Involve the MSM community in agency decisions regarding MSM programming.

Assessing Iowa's Cascade: From Diagnosis to Engagement in Care

Figure 15 shows Iowa's cascade of diagnosis and care. Data are obtained from the HIV surveillance system at IDPH, and are based upon viral load and CD4+ cell count data. Among the estimated 2,975 Iowans who are infected with HIV (back calculated based upon the number of persons living with HIV in Iowa regardless of state of diagnosis (2,327) and CDC estimates of undiagnosed persons (21%)), only 42% are receiving the care and treatment needed to attain an undetectable viral load (Figure 15).

Figure 15 Iowa's Cascade 2010



Evident in Figure 15 are the points along the cascade of care in which people are not progressing to the next level of care. Nearly 650 Iowans are infected but are unaware of their statuses and undiagnosed. Of the 2,327 who are diagnosed, 65 (3%) were never linked to care, 768 (33%) are not currently in care, and 1,081 (46%) do not have undetectable viral loads. This is problematic for multiple reasons. First, it means that a considerable number of PLWHA are not achieving optimal health outcomes and may be at risk for complications related to HIV. Increased costs related to healthcare, unemployment, disability, and loss of productivity have considerable effects on individuals, families, and the community as a whole. At the same time, these individuals are at a higher risk of transmitting the virus to their partners. The cascade is a tool to quantify where Iowa's system of HIV care needs the most attention. It also can be used to determine how limited resources can be used most effectively. In the coming sections, each of the steps of the cascade will be examined in more detail.

Without the funding to provide culturally relevant, uniquely tailored interventions to reach populations who are most at risk of becoming infected with HIV, a greater emphasis must be placed on the rest of the cascade to identify infected persons earlier, to prevent transmission to others, and to ensure positive health outcomes for people living with HIV disease.

HIV Testing and Diagnosis

Testing is one of the state's best opportunities for both prevention and care. It is estimated that 20% to 25% of people infected with HIV are undiagnosed (21% was used in the calculations above). Because a majority of new HIV transmissions occur from people who are unaware that they have HIV,[28] serostatus knowledge is in and of itself a prevention opportunity. In addition, among those who are in the acute period of HIV infection, generally within two to four weeks post-exposure, viral loads are particularly high. Viral load is the measurement of viral genetic material present in a person's blood. High viral loads indicate that the virus is rapidly reproducing, weakening the immune system, and increasing the risk of transmitting the virus to others. It is important, therefore, to provide testing for people as soon after exposure as possible, before they unknowingly expose others to the virus. Testing and diagnosis is also the first step in the linkage to partner services, care, and treatment.

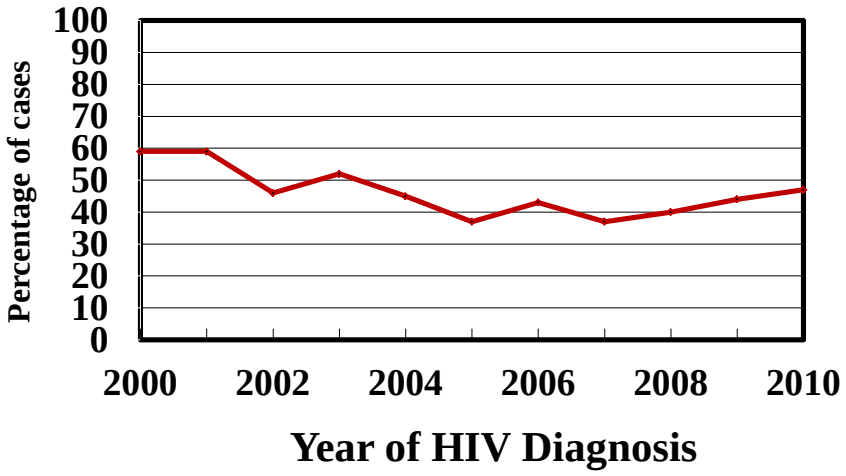
Late Testing

An important aspect of HIV testing is the number of people who delay testing and are not diagnosed until late in the course of the disease. Late testing, defined as persons diagnosed with HIV who receive a diagnosis of AIDS within one year, is associated with poor health outcomes and earlier deaths. Late testers benefit less from antiretroviral therapy, and they have more opportunities to transmit HIV to partners. According to a study by the Centers for Disease Control and Prevention, late testers are more likely than early testers to have been previously tested. The authors of the study surmised that, because they previously tested negative, late testers may erroneously presume they are not at risk and may not retest.[29]

Forty-seven percent of persons diagnosed with HIV in Iowa in 2010 received a diagnosis of AIDS within one year. This was an increase from 37% in 2007 and compares to 38% nationally from 1994 to 1999 (Figure 16).

According to the CDC study, men are more likely than women to delay testing, and members of racial and ethnic minorities are also more likely to be tested later than others. Heterosexual risk and injection drug use are the risk factors associated with the highest number of late testers.

Figure 16 Percentage of HIV Cases with Late Diagnoses (AIDS diagnosis made ≤ 12 months from HIV diagnosis



[28] Marks G, Crepaz N, Janssen RS. 2006. Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. AIDS. 2006 Jun 26;20(10):1447-50.
[29] CDC. Late HIV Testing--- 34 States, 1996-2005. MMWR June 26, 2009 / 58(24);661-665. (see http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5824a2.htm)

According to the 2011 Iowa Consumer Needs Assessment, 29% of respondents (116/374) delayed testing because of HIV-related stigma.

Barriers to early testing include not perceiving yourself to be at risk, having a healthcare provider who doesn't perceive you to be at risk or who does not prioritize HIV testing, not wanting to know your status (i.e., denial), and the stigma associated with HIV. Because HIV prevention funds are limited, the IDPH-supported CTR sites focus on only high-risk and disproportionately impacted populations. Cases may be missed among those who do not realize they are at risk. Other barriers may include the limited number of public testing sites, limited outreach testing, and the location of existing testing sites. Another possible barrier to testing is Iowa's criminal transmission law, which may have an unintended consequence of discouraging testing. Specifically, when a person does not know his or her HIV status, the person cannot be prosecuted under the law because s/he did not knowingly expose others to the disease.

Iowa recently attempted to pilot emergency room HIV testing in one hospital through the Ryan White Part B early intervention services program. Barriers to testing were very evident in this project. Busy providers often did not remember to offer an HIV test or did not prioritize it among the many needs of someone who may present in the emergency room. A current initiative is in progress to pilot testing at community health centers in higher-prevalence areas of the state.

Opt-out HIV testing for pregnant women was required in Iowa as of July 1, 2007. By law, all pregnant women must be tested for HIV unless they actively decline the test. In addition, select family planning clinics provide HIV testing through Title X HIV Integration Projects. Women at these clinics receive testing as part of their annual routine exams.

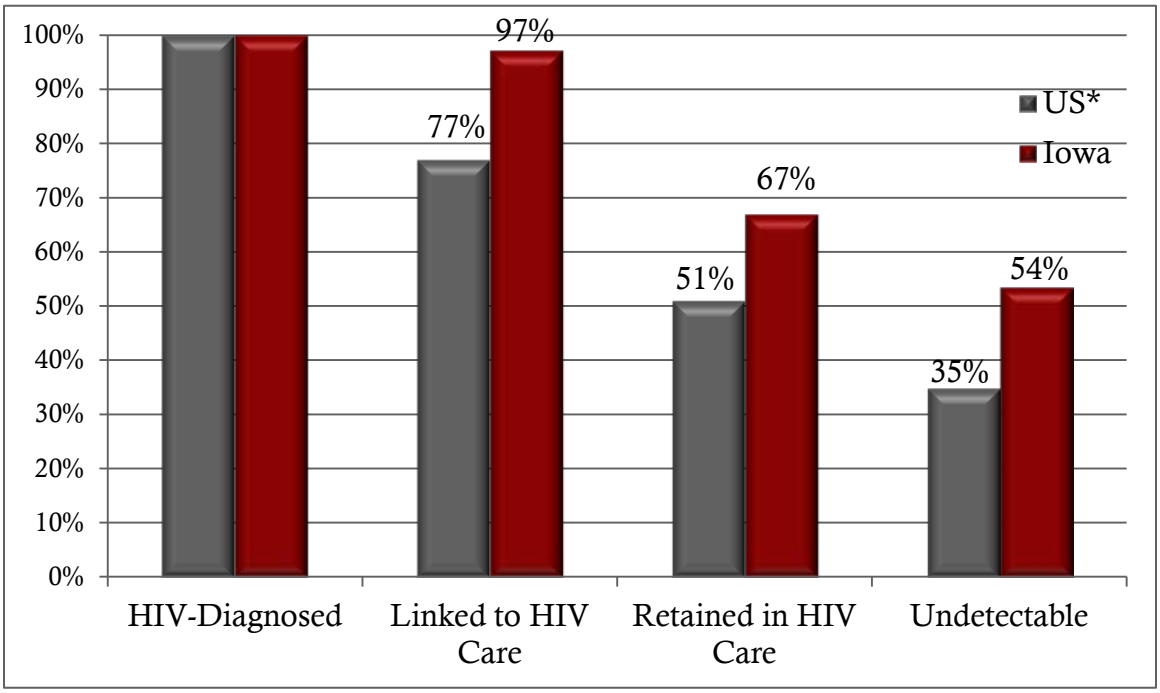
To evaluate testing efforts, IDPH-supported agencies are monitored to ensure they reach high-risk and disproportionately impacted populations. Efforts to identify newly infected persons have been improved recently by raising these standards and expectations for the agencies. In 2010, agencies worked toward a performance measure of 80% of all HIV tests administered to persons from high-risk or disproportionately impacted populations. As a means to achieve this, contracted agencies have improved accessibility to services by extending service hours and increasing outreach efforts. In addition to increased standards and expectations, contractors have been and continue to be provided ongoing training regarding the role of social determinants of health in increasing the risk of transmission in specific populations.

Finally, the provision of tests results has been greatly improved by the transition to rapid testing. Iowa's success with the provision of positive tests results continues as a result of strong relationships between regional disease prevention specialists and staff at testing sites. Reaching MSM remains a gap. Only 17% of tests at IDPH-supported test sites were among MSM in 2010, whereas 54% of positives in the state were among MSM.

Linkage

For further evaluation of Iowa's cascade, it can be helpful to compare the number of diagnosed Iowans who were linked to care with estimates of linkage across the United States. Linkage was measured by the performance of a viral load of CD4+ cell count within a year after diagnosis.

Figure 17 Cascade 2010



*CDC MMWR

Overall, Iowa performs better than national averages, particularly at linking newly diagnosed persons to care (Figure 17). Nonetheless, opportunities to improve in all parts of the cascade exist.

In Iowa, linkage is ensured by partner services staff (i.e., disease prevention specialists). All IDPH-supported testing sites refer positive clients to care, but the DPS follow up when they are delivering partner services. Despite the high percentage of persons linked to care, IDPH has not had a formal process for reviewing surveillance data routinely to identify those who were not linked to care. Protocols and timelines are currently under development.

These data show that linkage is a particular strength of Iowa's program. Testing counselors, case managers, peer support, and medical providers also play an important role in the success of Iowa's linkage programming.

Access and Retention

As Figures 17 clearly demonstrates, a considerable number of HIV-positive Iowans leave care after the initial linkage. It is estimated that approximately 33% of Iowans diagnosed with HIV were out of care at the end of 2010.

Disparities in access to quality HIV care correlate with differences in survival rates, as reflected in AIDS mortality rates.[30] The Health Resources and Services Administration HIV/AIDS Bureau, in coordination with the National Quality Center, has developed the in+care Campaign. The goals of the program are to bring patients back to care and to keep others from falling out of care. Freeze frame shots have been taken of the in+care Campaign public service announcement (PSA) to demonstrate the concepts related to access and retention. The PSA can be seen in its entirety at www.incarecampaign.org.

2010 Estimated Unmet Need for Primary Medical Care

In 2000, Congress included a mandate in the Ryan White Care Act for Ryan White Part B grantees to calculate and respond to unmet need for HIV primary medical care among PLWHA. "Unmet need" refers to the number of HIV-positive individuals who are aware of their infection but who are not receiving HIV primary medical care.[31] HIV primary medical care is defined as receiving at least one viral load or CD4+ cell count during the year, or being on antiretroviral therapy at some point in a given year. In the United States, the CDC estimates that one-third of people diagnosed with HIV are not receiving the regular medical care necessary to:

- Educate them about HIV disease and its transmission;
- Manage their infection, diagnostics, and treatment; and
- Ensure them positive health outcomes and longer lives.[32]

[30] HRSA Care ACTION, August 2002
[31] Connecting to Care, 2005 Regional Training on Addressing Unmet Need in HIV.
[32] "Advancing HIV Prevention: New Strategies for a Changing Epidemic --- United States, 2003", MMWR Weekly 52(15), 18 April 2003

The HIV surveillance office at IDPH conducts an annual study of who is out of care in Iowa. The most recent estimate of unmet need for HIV primary medical care was conducted using data from the enhanced HIV/AIDS Reporting System (eHARS). All persons diagnosed with HIV disease as of September 30, 2010, and living and residing in Iowa as of December 31, 2010, were selected for the analysis of unmet need. This includes people who had been diagnosed in other states but who had later moved to Iowa (NOTE: These numbers differ slightly from the estimates in Figure 15 above. This is because surveillance is a dynamic process, and estimates change as more information becomes available).

Of the 2,326 persons reported to be living with HIV/AIDS as of December 31, 2010, 1,577 (68%) had received HIV primary medical care during the specified time period, while 749 (32%) had no evidence of HIV primary medical care in 2010. Table 8 on the next page presents an analysis of those persons classified as "in care" and "out of care." The data in Table 8 suggest that, among the group of individuals reviewed, proportions of persons *out of care* were highest among those who were members of a racial minority, were MSM who also inject non-prescription drugs, were born outside the U.S., resided in rural counties, and had not yet progressed to AIDS (i.e., had an HIV diagnosis only). Persons out of care also had a longer time since diagnosis (11 years compared to 9 for persons in care). Based on the study, the following characteristics were disproportionately represented among people who were out of care:

- Hispanic/Latino(a) persons (46% out of care);
- Foreign-born persons (44% out of care);
- MSM/IDU (41% out of care);
- Persons with HIV diagnoses, but without AIDS diagnoses (36% out of care);
- Black, non-Hispanic persons (42% out of care);
- Persons from rural areas (35% out of care);
- Years since diagnosed, mean of 11.1 years.

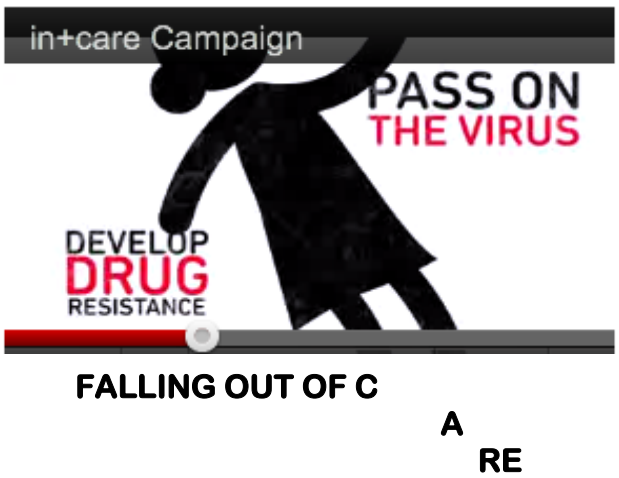


Table 8 Characteristics and Status of Care for Persons Living in Iowa with Diagnosed HIV Disease on September 30, 2010, and Who were Alive through December 31, 2010

	PLWHA Total = 2,326 No.	(Row %)	In Care Total = 1,577 No.	(Row %)	Out of Care Total = 749 No.	(Row %)	Odds Ratio	p-value	95% Confidence Interval
Diagnostic Status									
HIV	920	(100)	589	(64.0)	331	(36.0)			
AIDS	1,406	(100)	988	(70.3)	418	(29.7)	1.33	0.0016	1.11, 1.58
Sex at Birth									
Male	1,855	(100)	1,260	(67.9)	595	(32.1)	1.03	0.7968	0.83, 1.28
Female	471	(100)	317	(67.3)	154	(32.7)			
Race/Ethnicity								<0.0001*	
White, Non-Hispanic	1,561	(100)	1,128	(72.3)	433	(27.7)			
Black, Non-Hispanic	488	(100)	285	(58.4)	203	(41.6)	0.54	<0.0001	0.44, 0.67
Hispanic	186	(100)	101	(54.3)	85	(45.7)	0.46	<0.0001	0.33, 0.62
Asian	32	(100)	25	(78.1)	7	(21.9)	1.37	0.4627	0.59, 3.19
Multi-race	46	(100)	33	(71.7)	13	(28.3)	0.97	0.9379	0.51, 1.86
Other	13	(100)	5	(38.5)	8	(61.5)	0.24	0.0069	0.08, 0.73
Mode of Exposure								<0.0001*	
MSM	1,149	(100)	810	(70.5)	339	(29.5)			
IDU	250	(100)	161	(64.4)	89	(35.6)	0.76	0.0580	0.57, 1.01
MSM/IDU	225	(100)	132	(58.7)	93	(41.3)	0.59	0.0005	0.44, 0.80
Heterosexual	392	(100)	279	(71.2)	113	(28.8)	1.03	0.7992	0.80, 1.33
NIR	270	(100)	168	(62.2)	102	(37.8)	0.69	0.0082	0.52, 0.91
Pediatric	18	(100)	15	(83.3)	3	(16.7)	2.09	0.2357	0.60, 7.28
Other	22	(100)	12	(54.6)	10	(45.4)	0.50	0.1052	0.21, 1.17
Birth Country									
U.S.	2,015	(100)	1,404	(69.7)	611	(30.3)	1.83	<0.0001	1.44, 2.34
Other	311	(100)	173	(55.6)	138	(44.4)			
County of Residence									
Urban	1,441	(100)	998	(69.3)	443	(30.7)	1.19	0.0548	0.99, 1.42
Rural	885	(100)	579	(65.4)	306	(34.6)			
SELECTED SUMMARY STATISTICS	**PLWHA Total = 2,326**		**In Care Total = 1,577**		**Out of Care Total = 749**			**p-value**	
Years HIV Positive	Mean = 9.9 SD = 6.5 Median = 9.0 Range: 0 to 28		Mean = 9.3 SD = 6.5 Median = 9.0 Range: 0 to 28		Mean = 11.1 SD = 6.3 Median = 11.0 Range: 0 to 27			<0.0001**	
Current Age **(n=2,312)**	Mean = 45.1 SD = 11.0 Median = 46.0		Mean = 45.3 SD = 11.1 Median = 46.0		Mean=44.8 SD=10.9 Median=45.0			0.1373**	

Source of Data: Iowa Department of Public Health – Bureau of HIV, STD, and Hepatitis – HIV/AIDS Surveillance Program.

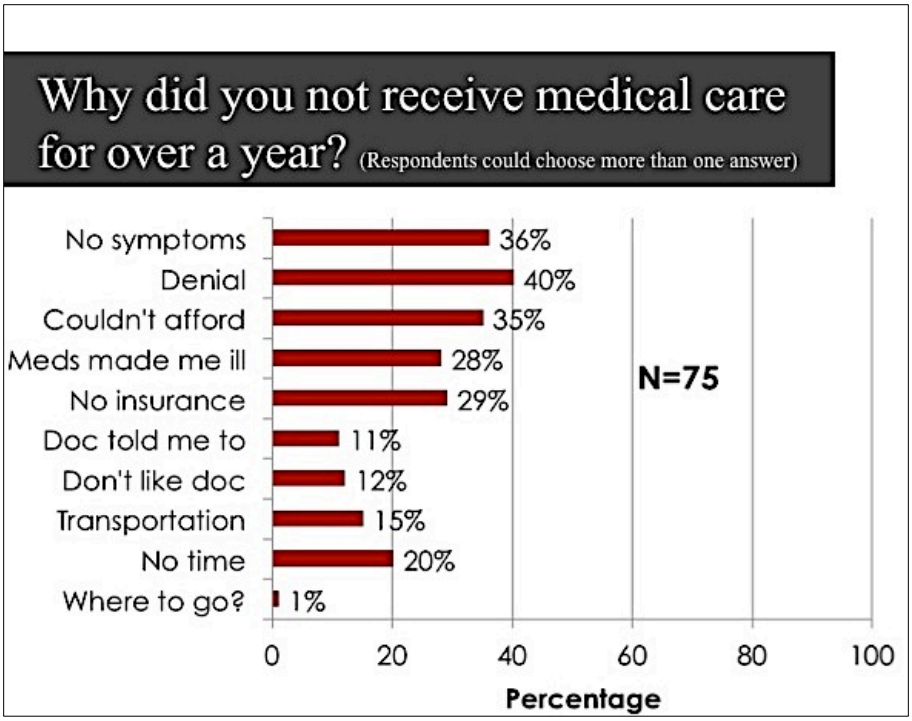
Notes for Table 8

PLWHA: persons living with HIV or AIDS with current residence in Iowa.
In Care: any person with a value of CD4+ count, CD4+ percent, or HIV viral load reported during 2010.
Out of Care: any person without a value of CD4+ count, CD4+ percent, or HIV viral load reported during 2010.
Odds ratio: way of comparing whether the odds of a certain event are the same for a comparison group as for a baseline group. In this case, an odds ratio greater than one (1) implies that the odds of being in care are greater in the comparison group than in the baseline group (in the table, the ones with no odds ratio shown are the comparison groups). For example, the odds ratio for the group of persons born in the U.S. is calculated to be 1.83. This is interpreted to mean persons born in the U.S. (the comparison group) are 1.83 times more likely to be in care than persons born in another country (the baseline group).
P-values: reflect chi-square results for general association across all strata shown for a particular variable. Represent the probabilities that the observed care differences happened purely by chance.
***P-values for Race/Ethnicity and Mode of Exposure groups:** represent the probability that care differences among all strata in the groups happened purely by chance.
****P-values for continuous variables (Current Age and Years HIV Positive):** reflect Wilcoxon-Mann-Whitney results for comparison of distribution medians.
95% Confidence Intervals: interpreted to mean there is a 95% certainty that the "true" value of a particular odds ratio falls within the calculated limits of the confidence interval.
SD: standard deviation from the mean
Current Age: age at time of this analysis. As of the time of this analysis, fourteen of the 2,326 persons alive as of December 31, 2010 had died, resulting in n=2,312 for the Current Age variable.
Urban versus rural classification: pools the top ten most populous Iowa counties in the urban category and all other counties in the rural group.
Multivariate logistic regression model: gives estimates as shown in table 2, with each estimate adjusted for all other variables in the model. These results suggest that, among the group of individuals reviewed, persons *out of care* were more likely to have HIV (non-AIDS), be members of a racial minority, have been born outside the U.S., reside in rural counties, or have lived longer since having been diagnosed with HIV.

Stated Reasons for Disengaging From Care

Navigating a healthcare system is challenging even for the most organized among us. People living with HIV/AIDS often must overcome many obstacles in accessing and maintaining care.

Figure 18 Reasons for Being Out of HIV Care



According to the 2011 CNA, 97% of respondents indicated being in HIV primary medical care at the time they filled out the survey. However, 21% of those respondents admitted to being out of care for at least a year at some point. The top ten reasons reported for choosing to disengage from medical care are outlined in Figure 18.

The part of Iowa's cascade that contains the highest level of "loss" is in the area of retention in care. Although linked to care initially, approximately one-third of HIV-positive Iowans are out of care in a given year. This number is significantly lower than the national average; however, this is the part of the cascade with the most opportunity for improvement. Re-engaging this group of people living with

HIV in medical care could have a large impact on Iowa's epidemic. Health outcomes would improve at the individual level and the likelihood of HIV transmission would be reduced.

Re-engagement in Care

A solution is to help HIV-positive individuals establish a continuous relationship to primary medical care within the context of their whole lives. To achieve this goal, it is important to identify and implement activities in diverse agency settings with the objective of connecting HIV-positive people to medical care and helping them stay connected.[33]

As mentioned previously in this document, care providers are beginning to focus on re-engaging people who are out of care. In FY 2012, two central Iowa providers teamed up to initiate a re-engagement effort. The Ryan Part B case management and support services provider and the Ryan White Part C clinic are collaborating to provide outreach services to individuals who have been clients in the past and have fallen out of care. The two entities worked to identify clients/patients who were no longer in care and are working with the IDPH to verify out-of-care status. An engagement specialist has been jointly hired by the agencies to provide referral and support services to clients identified as lost to care or at risk for becoming so. The goal of the program is to help clients identify and address barriers to accessing care. After 6 months of participation in the program, the specialist will transition clients to medical case management. Pending program outcomes, this program can be replicated in other parts of the state.

The IDPH is also exploring opportunities for the disease prevention specialists to conduct re-engagement activities for people no longer accessing care services. This new role for the DPS will

[33] Connecting to Care, 2005 Regional Training on Addressing Unmet Need in HIV

have to be weighed against current partner service priorities, including an ever-increasing number of chlamydia diagnoses and the threat of antibiotic-resistant gonorrhea.

Re-engagement programs will need to address most of the same barriers that have an impact on retention. The Plan Development Committee determined that the barriers to access and maintain engagement-in-care services have not greatly changed in recent years. The following section describes these challenges and the impact they have on Iowans living with HIV.

Barriers to Care and Attaining Viral Suppression

Despite the success of a number of initiatives that have increased access to care services in Iowa, barriers remain. Poverty, lack of transportation, stigma, cultural barriers, provider challenges, substance abuse, mental illness, and other factors impede not only access to care services, but also the likelihood of attaining an undetectable viral load. Even among PLWHA who were engaged in care at the end of 2010, 19% had not attained viral suppression. The following section describes the barriers that both affect access to care and attainment of positive health outcomes.

It should be noted that although the barriers to accessing care are complex, the most important crosscutting issue is lack of funding. Increased funding could be used to:

- Establish retention and re-engagement programs;
- Establish specialty satellite clinics throughout the state to address transportation needs;
- Implement programs that reduce stigma and discrimination;
- Provide HIV/AIDS education for providers;
- Offer HIV testing as part of routine medical care;
- Fund substance abuse and mental health treatment so that people in need are not turned away;
- Increase supportive service program staffing to handle increased caseloads; and
- Expand assistance programs to include the working poor.

Until Iowa can secure sufficient funding to pursue these programmatic needs, it is necessary to continue to identify the greatest needs and barriers among the populations served and to work more efficiently and collaboratively within our communities and our current state infrastructure to accomplish our goals.

Self-Management and Adherence

Iowans living with HIV need to play an increasingly large role in managing their conditions. Each patient is at a different place in the process, and appropriate interventions are driven, to a large extent, by each patient's desired outcomes. To meet these needs, it is essential for patients to have the following:

- Basic information about HIV/AIDS disease and its treatment;
- Understanding of and assistance with self-management skill building; and
- Ongoing support from members of the practice team, family, friends, and community.

Self-management and adherence encompass all the activities PLWHA perform to control their illnesses, prevent future complications, and cope with the impact of both the disease and its treatment on themselves and others. They include:

- Collaborative goal setting;

- Monitoring of symptoms;
- Lifestyle behaviors such as eating a healthy diet, getting regular exercise, and smoking cessation;
- Taking medication in the dose and frequency prescribed;
- Communicating with the healthcare team, family members, and others; and
- Ongoing problem-solving to overcome potential barriers.

People with chronic conditions must make ongoing adaptations in their daily lives as they face the many emotional and physical challenges their disease presents. Providers need to be sensitive to the role that families, caregivers, and communities play in different cultures. Better patient outcomes are achieved through use of evidence-based techniques that emphasize patient activation or empowerment, collaborative goal setting, and problem-solving skills.

Iowa could enhance its ability to support PLWHA by using standardized assessments that include questions about self-management, such as knowledge of the disease and its treatment, communication skills, confidence, supports, and barriers to care. Self-management efforts could further be supported by emphasizing the role of the patient, by recommending and using effective interventions, and through the use of care planning and problem solving to help patients overcome barriers to self-management activities.

Socioeconomic Status and Poverty

Demographic trends indicate that the number of Americans vulnerable to suffering the effects of healthcare disparities will rise over the next half century. Current data show that low-income families, whatever their races or ethnicities, tend to be in poorer health than other Americans. Gaps in income between the richest and poorest households in America are widening.[34] The most striking health disparities involve shorter life expectancies among the poor, as well as higher rates of cancer, birth defects, infant mortality, asthma, diabetes, and cardiovascular disease. Unequal access to healthcare accounts for much of this disparity.[35]

Poverty-related issues significantly impact the ability of many PLWHA to access and remain in medical care. The likelihood of co-existing conditions, such as mental illness or substance abuse, is also substantially increased. In addition, many Iowans living with HIV require assistance with meeting basic needs like food, shelter, and transportation. Compounding this, the economic downturn and natural disasters, such as the floods and tornadoes, have impacted low-income Iowans

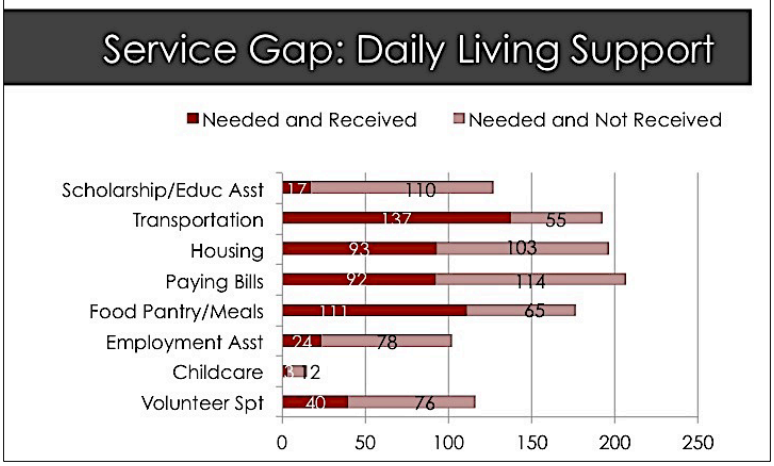
[34] Agency for Health Care Research and Quality, US Department of Health and Human Services, http://www.ahrq.gov/qual/nhdr03/nhdrsum03.htm#ref2, Accessed, July 2006

[35] National Institute of Environmental Health Sciences, National Institute of Health, US Department of Health and Human Services, http://www.niehs.nih.gov/oc/factsheets/disparity/home.htm, Accessed July 2006

by displacing them through loss of homes and/or employment, forcing many to move in with family or to move to other communities.

According to the U.S. Bureau of Labor Statistics, unemployment in Iowa increased from 3.8% in January 2008 to a high of 6.9% by April 2010. It was at 5.5% as of August 2012. This increase has caused more Iowans to be in need of access to healthcare services and has depleted resources for many Iowans who are out of work.

Figure 19



The 2011 Consumer Needs Assessment identified the daily living service needs shown in Figure 19. The lighter area of the bars represents the service gaps. Help paying bills, educational assistance, housing, employment assistance, volunteer support, food banks, and transportation were indicated as the categories of support that were needed but not received by survey respondents.

Transportation

Iowans living with HIV travel great distances to access providers. Few specialized HIV medical providers practice in rural areas, limiting access to medical care for PLWHA. Federally funded primary medical providers are located in four cities in Iowa, as well as in Omaha, NE. This means that many rural Iowans must travel great distances to access their services.

According to the 2011 CNA, 23% of respondents drive more than 60 miles one-way to reach a medical clinic. Nearly one-third of these individuals drives more than 100 miles one-way to access HIV specialists and support services. Twenty-seven percent reported travelling at least 2 hours round-trip to access services, and 7% of these respondents travelled between 4 and 8 hours round-trip.

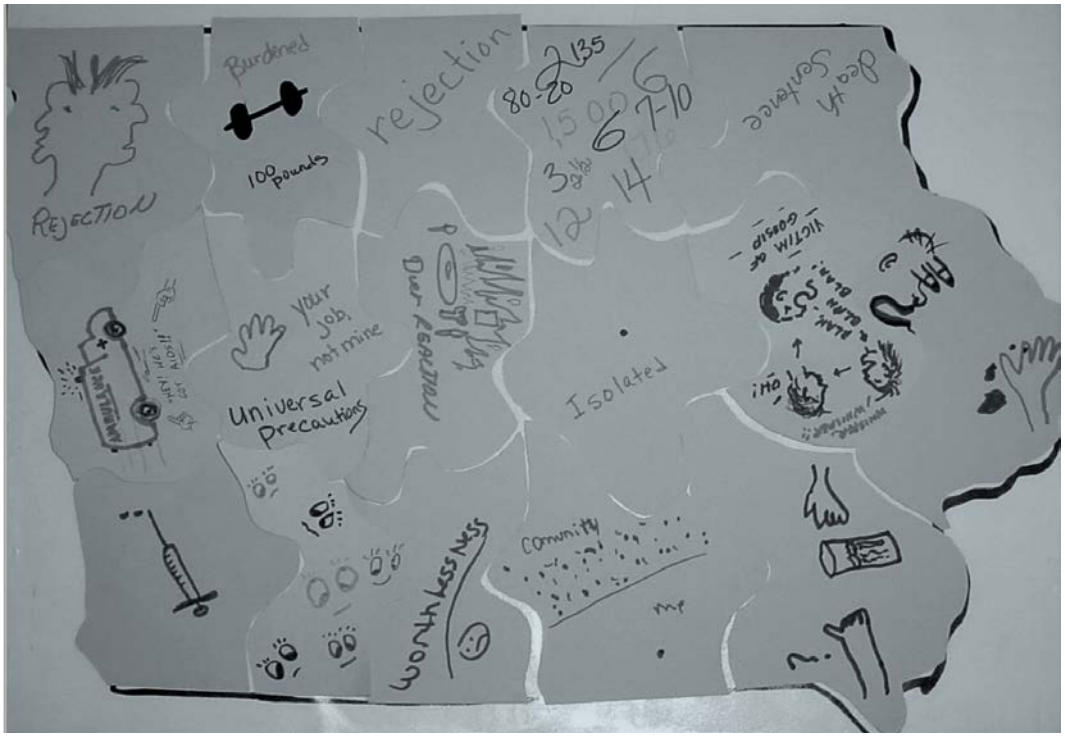
Thirty-seven percent of clients responding to the 2011 CNA had used transportation services to get to appointments in the past 12 months. Thirteen percent who had used these services found them difficult to access. Another 30% said the service was unavailable to them, but that they would use it if it were available.

Transportation barriers exist in both rural and urban locations. Rural patients may not have access to any form of public transportation and may live hours from core

services. Some clients who live in urban areas find it difficult to get to their appointments because the agency is located blocks from the bus stop or in a neighborhood where sidewalks are not available. Volunteers from some organizations drive patients to their appointments, but strong networks of buddy systems and volunteers have declined. Providers often do not have the time to coordinate transportation for clients or the funds to meet clients' transportation needs. For example, increases in gasoline prices have made mileage reimbursement more difficult for agencies and community groups.

Stigma

Throughout history, societies have stigmatized groups of all kinds for various reasons, mostly as a result of ignorance, misconception, and superstition. AIDS is a disease –nothing more.[36] Nevertheless, people living with HIV/AIDS have always been confronted with stigma and often face overt and covert discrimination. Outside of established AIDS service organizations and specialized clinics, clients encounter ignorance, bias, and lack of education about HIV disease. Limited funding to educate community members and those who deliver systems of care remains a barrier to reducing stigma. Therefore, the stigma associated with HIV remains pervasive in many areas where PLWHA work and live, and sometimes it even permeates the systems established to provide care. Because stigma often prevents people from accessing or remaining in care, it is important to view other issues through the lens of stigma.



Stigma Puzzle from Positive Iowans Taking Charge (PITCH) describing the impact of HIV-related stigma.

Theodore de Bruyn, who has studied stigma among persons with HIV/AIDS, says that "stigma and discrimination feed on cultural differences and block out common humanity. This happens through social processes whereby the negative associations of HIV/AIDS lead people – inadvertently or deliberately – to shun, avoid, shame, degrade, or discriminate against PLWH."[37]

[36] HRSA CARE ACTION, August 2003

[37] HIV/AIDS and Discrimination: A Discussion Paper by Theodore de Bruyn

ISBN 1-896735-14-2

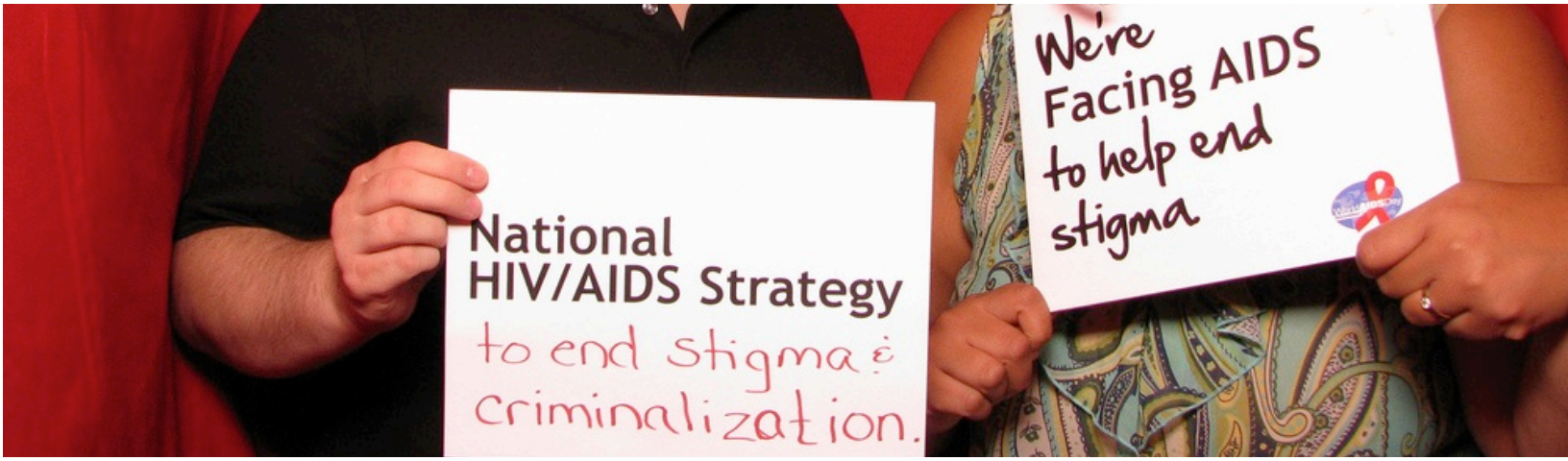
According to the World AIDS Campaign:

> *"Stigma and discrimination are the major obstacles to effective HIV/AIDS prevention and care. Fear of discrimination may prevent people from seeking treatment for AIDS or from acknowledging their HIV status publicly. People with, or suspected of having, HIV may be turned away from healthcare services, denied housing and employment, shunned by friends and colleagues, refused insurance coverage or entry into foreign countries. In some cases, they may be evicted from home by their families, divorced by their spouses, and suffer physical violence or even murder."*[38]

Stigma and Healthcare

The healthcare system can be a source of stigma. Healthcare professionals, particularly those who infrequently encounter people living with HIV/AIDS, such as in rural areas, may be unaware of and, therefore, insensitive to issues associated with HIV that generate stigma. These issues include sexuality, cultural origin, mental health needs, and substance abuse issues. Conversely, healthcare professionals in urban areas, who deal with HIV/AIDS on a daily basis, may become less sensitive to the stigma their clients may face. Procedures for maintaining patient comfort and confidentiality in these areas may be lax or not adhered to by all agency employees.

Healthcare providers may fear their own stigmatization because of their work with HIV-positive patients. The prevalence of such fears may have declined over time, but they have not been eliminated.[39]



Impact of Stigma

According to the 2011 Consumer Needs Assessment, a majority of respondents indicated that stigma had a strong impact on their decisions about serostatus disclosure. Eight-six percent of respondents said they were very careful to whom they disclosed their HIV status, and 78% stated that telling someone they have HIV is "very risky." Sixty-three percent of participants said they work hard to

[38] World AIDS Campaign 2002-2003 on eliminating stigma and discrimination.
[39] HRSA CARE ACTION, August 2003

keep their HIV a secret, and only 32% felt that they didn't need to hide their HIV status. Another 59% want to share their story with others but don't due to the fear of stigma.

The fear of serostatus disclosure is rooted in a concern about discrimination and inequality. Eight-three percent of survey respondents worried they would be discriminated against when people found out they have HIV, and 63% agreed that PLWHA lose their jobs due to stigma. These beliefs are rooted in personal experiences that have led 56% of respondents to feel isolated. Moreover, 40% reported that when others found out they had HIV, the other persons physically backed away from them.

Other populations have been studied to determine the effects of not feeling able to share an important part of one's life or of living with a "secret." Links to stress and anxiety have been demonstrated, as have effects on physical health, such as blood pressure, heart health, immune system functioning, digestion, fatigue, and pain (muscular, headaches, etc.). Prolonged periods of stress and anxiety can lead to chronic health problems.

The stigma associated with HIV status disclosure can have an obvious impact on HIV prevention efforts. Twenty-nine percent of survey participants stated they waited to get an HIV test due to stigma. Stigma also creates a culture in which people living with HIV may be less inclined to share their HIV status with potential sex partners. PLWHA who use injection drugs may also be unlikely to share their HIV status. This may allow others to use a syringe that was previously used by the person with HIV.

Iowa has a law that has led to the prosecution of PLWHA who didn't disclose to their partners before intimate contact occurred. Studies have shown that legal deterrents do not work as well as public health tools and messaging. In fact, this law is itself a source of stigma. No other life-threatening diseases include similar legal requirements. The law places the full burden of disclosure on PLWHA rather than acknowledging the obligation that everyone has to talk to their partners about HIV and STDs and to discuss prevention options.

Cultural Barriers

Cultural barriers to receiving care must also be addressed. According to a 2002 HRSA report:

> *"Cultural differences between providers and patients affect the provider-patient relationship. How patients feel about the quality of that relationship is directly linked to patient satisfaction, adherence, and subsequent health outcomes. It has also been shown to influence whether patients continue to see a physician or even remain enrolled in a healthcare plan. If the cultural differences between patients and providers are not recognized, explored, and reflected in the medical encounter, patient health outcomes may suffer."*

Bridging cultural differences presents a challenge, however. One problem that both patients and providers bring to their interaction is biases, many of which are rooted in culture."[40]

[40] HRSA Care ACTION, August 2002.

Differences in language, sexual orientation, gender, and race/ethnicity may inhibit clients from accessing and/or maintaining care. A disproportionate number of racial and ethnic minorities are affected by Iowa's HIV epidemic. As described in Section 1 of this document, 2% of the general Iowa population is black and 5% is Hispanic; however, 20% of Iowans living with HIV are black and 8% are Hispanic. Significant portions of both of these populations are foreign born. Overall, 15% of PLWHA in Iowa are foreign-born, but significantly higher proportions of newly diagnosed cases are among foreign-born persons. In 2011, 22% of diagnoses were among foreign-born persons. The Iowa counties with the largest percentage of Latino residents are Crawford and Buena Vista (each at 22 percent), Louisa (17 percent), Marshall (16 percent), Muscatine (15 percent), Franklin (14 percent), Woodbury (12 percent), Wright (10 percent), and Allamakee (9 percent). The Ryan White Part C Clinic in Sioux City reports that 24% of their clients are Hispanic and nearly one-third of clients at the Part C clinic in Des Moines are black.

Speaking a different language than the predominant population is a major barrier to clients accessing and understanding their care. Many clients introduce a young child or other family member into the client-provider relationship to serve as an interpreter. Due to the nature and context of this disease, it is less than optimal to rely on a child or other family member as an interpreter. Variations on the following scenario have been reported across Iowa. It serves as an example of how this issue can interfere with clients staying in care:

"Hector" is originally from El Salvador and only speaks Spanish. He goes to his health clinic to see a physician for HIV care. The physician needs interpretation in order to treat Hector, so he calls in the Spanish-speaking receptionist to help. Hector is taken by surprise; the receptionist is related to his boss at work. Now, he fears that she will tell his boss that he is HIV positive and that word will spread throughout the small Latino community in his town. He leaves the clinic upset and afraid.

Within specific communities, cultural norms create barriers for understanding HIV disease. Persons living with HIV in these communities may find it difficult to access medical and support services. For example, many Latino cultures dictate that through 'machismo,' a man is strong and should not have to rely on anyone but himself. Presented with the need to seek medical attention, men often choose not to access care so as not to appear weak.

With the epidemic increasing among women, cultural issues arise that are not present in the male community. Consider the influence of *marianismo* among some Hispanic women. Latin-American women are often treated as subservient, are held in less esteem, and are not allowed to seek outside help or attention unless the dominant spouse has given permission.

The strong presence of the church in the Latino community leads to a sense of deserved guilt that keeps clients from seeking services: "I must have done something wrong; God is punishing me with this disease." Clients may resign themselves to suffer instead of seeking assistance.

The presumption by a large portion of the Latino community that if you have HIV/AIDS, you must be gay may hinder a client's ability to seek support and services.

Iowa has served as a resettlement site for HIV-positive refugees from Africa. The African-born population also has barriers, such as language, cultural norms, or even the small size of the immigrant population that inhibit accessing some types of support. Clients from some populations believe they have been cursed with this disease by an enemy, and that only culturally specific medication or healers can cure them. Women in these communities are relegated to a subservient role. They may not be allowed to seek outside care without permission from the dominant male. Finally, the small size of the immigrant population may make some persons reluctant to attend any support groups or a particular clinic. The fear that someone will spread word of a person's HIV status to the community can be a strong deterrent to participation or attendance.

Fear of deportation, including deportation for having HIV, may also discourage many foreign-born individuals from accessing care. In 2008, federal immigration raids at meat-packing plants in Iowa resulted in the arrest of hundreds of suspected undocumented persons, primarily members of the Latino community.

Other than Spanish, there is a lack of translated educational materials and few appropriate interpreters to communicate between providers and clients. Even Spanish translation is a challenge in some of the more rural areas of the state. Iowa also has geographical pockets of Vietnamese, Congolese, Sudanese, Somali, and other minorities. Clinics serving PLWHA report these populations are increasing, and so are challenges related to translation and interpretation services. Every minority community has specific needs that not all service providers have been adequately trained to address. Often providers have not had opportunities to seek additional training to meet the needs.

Challenges for Care Providers

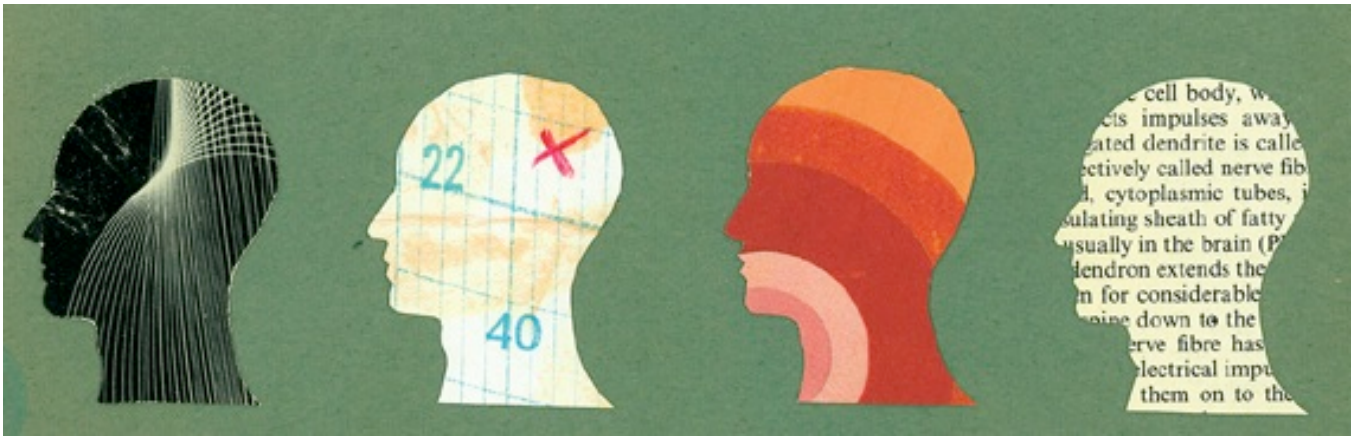
People living with HIV often appear in rural emergency rooms or at general practitioner offices. The providers may believe that HIV is not a problem in the area. They may not conduct proper patient risk assessments, and may, therefore, miss cases. Misdiagnoses and improper diagnoses have been

reported in rural Iowa, resulting in patients not receiving timely care. Rural physicians may be reluctant to become known as "the AIDS doctor," for fear of scaring off other patients.[41] However, the possibility of establishing satellite clinics by utilizing new technology such as telemedicine to deliver health and supportive care services is promising. Nevertheless, providers experience challenges in accessing funding for these clinics.

Well-trained providers are better able to help people living with HIV access and maintain care. Support service providers report difficulty maintaining updated knowledge of the various programs available for people living with HIV, and how to address the many biopsychosocial issues that affect their clients. Support service providers often wear many hats, and find it difficult to devote the time necessary to maintain this capacity.

Heavy caseloads contribute to service providers' difficulty in delivering the quality care that helps high-need clients stay in care. Ryan White Part B case managers saw 1100 clients in 2011, a number that has doubled since 2005 (550 clients). The increased caseload is due not only to the success of Highly Active Antiretroviral Therapy (HAART), but also to the migration of HIV-positive persons to Iowa. Many of these people may have become infected in urban centers in other states, but they have returned home to rural areas for care and to be closer to family members.[42] It is important to note that only persons diagnosed as residents of Iowa are counted in the federal funding formula for Ryan White services in Iowa.

Co-Morbidity (Substance Abuse/Mental Illness)



Active substance abuse and untreated mental health issues, including depression, are relatively consistent predictors of poor adherence to HAART[43] and poor health outcomes. This is due, in part, to this population's difficulty with accessing and maintaining care, including accessing harm reduction services. In 2010, 36% of HIV-positive injection drug users and 41% of MSM/IDU were not receiving HIV primary medical care, compared to 32% of all HIV-positive Iowans.[44]

[41] Frazier EM, Gabel LL. HIV/AIDS in family practice: an approach to care in rural areas. Family Practice Recertification. 1996;18:59-77.
[42] Rumley RL, Shappley NC, Waivers LE, et al. AIDS in rural eastern North Carolina. Patient migration: a rural AIDS burden. AIDS. 1991;5:1373-1378.
[43] New York State Department of Health. Adherence to antiretroviral therapy among substance users. New York (NY): New York State Department of Health; 2005 June
[44] 2010 Iowa Unmet Need study

Iowa has fought methamphetamine manufacturing and abuse since 1994. In 1994, there were two methamphetamine labs discovered in the state. This increased dramatically to 1,500 labs in 2004. To combat the problem of methamphetamine manufacturing, Iowa passed legislation that restricted pseudoephedrine purchases in 2005. As a result, Iowa experienced a drop in methamphetamine labs discovered, with a record low of 178 labs discovered in 2007. Since 2007, however, this number has increased. In 2010, 305 methamphetamine labs were discovered. According to the Iowa Drug Control Study, "Iowa still has the 10th highest number of meth treatment admissions and the 11th highest rate of meth treatment admissions in the nation (2009 TEDS)."[45]

Substance abuse and mental health treatment greatly improves adherence to medications and overall health. Since the core medical services requirement was implemented, the Ryan White Part B Program has increased funding for mental health services. As a result, several Part B service providers have mental health professionals on staff to provide these vital services. However, due to the current economic downturn, one service provider recently eliminated their mental health position. At this time, it is unknown whether this will be replicated with other Part B service providers. Regardless, insufficient funding limits PLWHA's access to needed mental health and substance abuse treatment.

In Iowa, substance abuse treatment is in short supply, even though it is critical for staying in HIV care and for adhering to a treatment regimen. Providers report that even when their clients are ready to receive care and a payer has been identified, there are often long waiting lists and the opportunity is missed. Furthermore, many clients are unable to access mental health medications. Mental health and addiction treatment are not well integrated with HIV care systems and HIV healthcare coverage. There are no clear guidelines regarding sharing of client-level information between systems, leaving case managers, treatment providers, and clinicians to navigate complex laws about sharing of confidential information.

The capacity of Ryan White service providers and case managers to provide mental health services needs to be addressed. Often these providers do not have the credentials or the time to provide the levels of mental health services or substance abuse counseling services that are needed.

Housing

A stable home environment is critical for persons managing complex drug therapies and potential side effects. Lack of adequate housing, however, affects a large number of persons living with HIV in Iowa, as evidenced by the 2011 CNA. Twenty-five percent of respondents reported receiving assistance. Among those not receiving housing assistance, 45% of them indicated a need for this service. Furthermore, 33% of respondents

[45] http://www.state.ia.us/government/odcp/docs/iowadrugtrends02071.pdf

reported having been homeless at some point in their lives. This number may be even higher, since many consumers are likely unaware of HUD's homelessness-defining criteria, which include staying with friends or family without adequate housing space.

Section 8 waiting lists of eight years or more are common throughout the state, which is why HOPWA is a very important resource for Iowa. HOPWA funds have been provided to Iowa since 2002. The program is designed to help very low-income Iowans living with HIV stabilize their housing situations, which is essential to health and well-being. Rental assistance and case management are provided to enable those on the verge of homelessness or in unsafe housing secure and maintain affordable, safe places to live. It is important to note, however, that the program cannot assist those who are already homeless, thereby leaving a considerable number of Iowans living with HIV homeless.

In some parts of Iowa, the need cannot be fully met by available resources. Indeed, some service providers must prioritize and can assist clients only on a short-term basis, for one to five months. Others are still able to assist for longer periods of time, but can serve fewer individuals and have had to implement waiting lists. Furthermore, due to the limited funding of HOPWA, many clients are told that funding is just not available, which deters them from asking for assistance again when they need it.

Other challenges exist for HOPWA providers and clients throughout the state. There is a scarcity of affordable housing units, which is exasperated in rural areas that meet HUD requirements for habitability. Identifying landlords who are willing to make required repairs or other changes to bring the units into compliance can be a challenge. Furthermore, there is a dearth of housing that is within close proximity to medical services. HOPWA providers lack funds and staff availability to meet client transportation needs.

Finally, housing discrimination remains a challenge faced by PLWHA. Whether related to HIV status, socio-economic class, past convictions, or poor rental or credit histories, discrimination often adds another layer of complexity concerning housing for PLWHA.

Dental Care

Access to dental care remains difficult for many clients, even for those with Medicaid. To assist clients without dental insurance, some Ryan Whit Part B client service providers partner with their Part C counterparts to utilize Ryan White Part C funding. However, due to a shortage in these funds, providers must prioritize and/or ration access. For example, one service region has a waiting list for dental assistance. Dentists are not required to accept Medicaid, and many dentists refuse to accept it. Medicaid reimbursement rates are a disincentive for many dentists to participate. Low reimbursement rates place many dental clinics that serve Medicaid and uninsured clients in

jeopardy of closing their doors. Furthermore, in an effort to contain costs, Medicaid does not cover all procedures that may be deemed appropriate by the dentist and client.

The 2008 CNA showed that 59% of respondents reported having received dental services. Among people who did not access dental care, 74% indicated they needed the service. Providers report encountering clients who have neglected their oral health. As a result, these clients have extensive dental care needs that go beyond the routine exam and cleaning. For example, methamphetamine users often have teeth that need to be extracted and replaced with false teeth. In most cases, Ryan White funding, Medicaid, and other assistance programs will not cover extensive dental care such as this. In addition, transportation issues may interfere with clients' abilities to keep a series of dental appointments, resulting in some clients being dismissed from dental clinics.

People Living Longer with HIV/AIDS

Over the past ten years, HIV has evolved from a terminal illness to a chronic disease, as HAART regimens have slowed the progression of infection and increased quality of life. As people with HIV live longer, providers face a number of new challenges that can impact keeping patients in medical care, including:

- Changing demographics, including foreign-born persons and continued increases in cases among minority populations;
- Increasing age of people living with HIV;
- Engaging and retaining HIV-positive people in care;
- Recognizing prevalence of co-morbidities, especially mental health issues, substance abuse, and hepatitis;
- Simplifying complex treatment regimens to maximize adherence;
- Identifying and managing long-term effects of HAART;
- Reducing disparities of HIV care between subpopulations;
- Integrating ongoing prevention counseling into care, including educating providers about strategies to help patients change behaviors and reduce risk;
- Managing general medical and preventive healthcare for people in middle age and the elderly;
- Differentiating treatment side effects from symptoms related to other common, non-HIV medical problems associated with aging.[46]

A thorough examination of several models for addressing these complex issues will be necessary in the near future.

Income Limitations

In Iowa, persons living with HIV must have an income of less than 200% of the Federal Poverty Limit, after allowing a $500 per month work deduction, to qualify for most Ryan White services. This income cap prevents many from accessing these services. Case managers routinely report that a significant number of people who do not qualify for Ryan White services are unable to pay private insurance premiums, co-pays, or the cost of medications needed for treatment.

[46] Agins, Bruce D., Medical Director, New York State Department of Health, AIDS Institute, excerpted from http://www.ihi.org/IHI/Topics/HIVAIDS/HIVAIDSExpertHost.htm

Clients qualified for Medicare and Medicaid may still be required to pay co-pays and premiums. There are concerns about the effectiveness of the Medicare Part D prescription drug programs because of the complexity of the plans offered and how HIV medications may not be covered entirely within the client's plan. As PLWHA are living longer, they also need to access healthcare services for other non-HIV-related medical conditions that may add to their overall expenses.

Since 2005, Iowa's AIDS Drug Assistance Program has received an ADAP supplemental award and state funding. Beginning in 2010, it also qualified for ADAP Emergency Relief Funding. However, the increase in PLWHA will necessitate increased funding to keep up with demand. Furthermore, the current economic climate may increase the need for assistance at a time when public funding may decrease or remain level.

Funding for Iowa's Ryan White Part B and C programs has not kept pace with increases in costs and clients. With a focus on increasing routine testing, it is expected that the client population will increase even more at a time when the funding for Part C clinics, in particular, decreases or remains level. Furthermore, reaching clients earlier in the disease process will result in higher long-term expenditures for treatment. In this environment, spending caps are quickly surpassed. Current projections indicate that, without an increase in budgets, both the ADAP and the support services program will face making cuts, resulting in substantial difficulties for clients in accessing care and maintaining drug regimens.

Cross-Cutting Issues

Coordination and Collaboration

A coordinated approach is needed to address challenges presented by the healthcare and service environment, gaps in information available to consumers, disparate and incomplete data systems, and co-existing conditions, such as mental illness, substance abuse, STDs, and hepatitis C. Coordination implies not only communication and sharing of information, but also shared understanding of the importance of working together to ensure a true continuum of HIV care at the client level.

Coordination issues are complex and challenging, and may involve service providers; clients; state and county public health agencies; other state agencies; federal agencies; private, community-based organizations; and public officials. The various federal and state funding streams for HIV prevention, medical care, and support services create inefficient silos, have duplicative reporting requirements but varying definitions for similar services, and foster a lack of coordination across the HIV continuum of prevention and care. Integrating approaches across disciplines and agencies requires an understanding of several philosophical approaches to prevention and treatment, as well as an understanding of the different priorities that each agency may have. The need for coordinated planning should be demonstrated to prevention service providers, local medical care providers, substance abuse treatment and mental health care providers, case managers, and other agencies that may affect or influence standards and protocols. With limited funding, agency coordination is essential to reduce duplication of services and to maximize current resources. Furthermore, coordination provides an optimal referral service delivery system for clients.

Prevention Service Providers

The implementation of the Affordable Care Act may have a significant impact on the delivery of preventive health services like testing, behavioral intervention, and delivery of immunizations. The existence of current safety net providers like family planning agencies, local public health departments, and AIDS service organizations may be challenged as more people are expected to have access to health insurance and other payers of primary health services. Major reductions in funding to agencies like CDC and HRSA are expected in 2014 and beyond, and these reductions will reach to the safety net providers. It is anticipated that IDPH will no longer have funding to provide to local safety net providers for direct services like testing and immunizations. These providers will need to find other revenue sources to continue to serve people in need.

One revenue source for safety net providers will be to bill Medicaid, Medicare, and other third-party payers for services when their clients are covered these programs. Currently, no local public health department bills for STD or HIV testing, although at least one has begun billing for immunizations. Creating the infrastructure to bill private insurance companies or Medicaid will take significant time and effort, and may also require changes in state Medicaid rules and policies.

Other prevention services will shift to community health centers and other primary care providers. Improving testing, linkage, and retention in care in the future will involve working more and more with providers who have been outside the traditional HIV service network. New partnerships and collaborations will be required.

The implementation of health reform in Massachusetts has demonstrated that reform does not eliminate the need for safety net providers.[47] In fact, the demand increased. Research shows that safety-net patients prefer the care delivered there, but they may also have other reasons for using safety net providers, such as maintaining privacy or avoiding explanations of benefits that insurance companies may mail to their policy holders. Moreover, a significant number of people will either be ineligible for insurance or public programs, or they may opt-out of the coverage despite the penalty that will accompany this.

Ryan White Grantees (Parts B, C, and MATEC)

Whether in a large metropolitan city or a rural area of the state, sharing success stories and challenges among programs can reduce duplication of services, as well as some of the time and effort required to develop or modify a program. It is especially important to avoid "reinventing the wheel" in a rural state with limited resources. Geographic distance, lack of time, and limited funding make it difficult for Ryan White grantees to create a forum where this kind of exchange can happen. Staff turnover, growing workloads, and lack of contact information are some reasons cited for limited communication. Grantees are not always sure what services other grantees' provide and whom they serve. To address these issues, Parts B, C, and MATEC have held networking meetings annually since the SCSN of 2005-2006.

Mental Health and Substance Abuse Systems

Active substance abuse and untreated mental health issues, including depression, are relatively consistent predictors of poor adherence to highly active antiretroviral therapies and poor health outcomes.[48] In Iowa, 40% of HIV-positive injection drug users are not receiving primary medical care. This compares to 32% of all HIV-positive Iowans.[49]

According to the 2011 Statewide Consumer Needs Assessment, 61% of respondents had been diagnosed or told by a physician they have symptoms of one or more mental health disorders. Anxiety (40%) and depression (54%) were the most frequently reported, with fewer indicating bipolar disorder (12%), post-traumatic stress disorder (11%), obsessive compulsive disorder (7%), and schizophrenia (2%). Only 43% of those with a mental health disorder had accessed treatment.

Twenty-eight percent of respondents reported use of illegal substances (not including alcohol and tobacco). Marijuana was the most

[47] Ku L, Jones E, Shin P, Byrne FR, Long SK. 2011. Safety-net providers after health care reform: lessons from Massachusetts. Arch Intern Med. 2011 Aug 8;171(15):1379-84.
[48] New York State Department of Health. Adherence to antiretroviral therapy among substance users. New York (NY): New York State Department of Health; 2005 June.
[49] 2010 Unmet Need Study.

frequently reported substance (21%). Thirty-nine percent of respondents said they felt a need to cut down on their drug or alcohol use.

It is important for HIV, substance abuse, and mental health professionals to be knowledgeable about available services and how to access them. For example, Iowa has an *Access to Recovery* program, which is a voucher system for substance abusers to access a variety of services, such as dental, housing, transportation, gas, clothing, nutrition, etc. The *Access to Recovery* program, with a budget of $5 million, is an excellent resource for HIV-positive clients with substance abuse issues. However, this program is currently underutilized by Iowans living with HIV.

It also is important that each professional understands specific issues related to each condition (e.g., HIV, substance abuse, and mental health) or knows where to go for reliable information about them. This enables each professional to provide optimal care for their clients and timely referrals to other services as needed. A system for coordinating and ensuring the care and treatment of all health conditions of Iowans living with HIV will result in better health outcomes and lower costs.

Mental health, substance abuse, and HIV have their own complex sets of services that generally operate independently of one another. Each system has its own culture, vocabulary, and acronyms. Professionals trained in one field often feel inadequate to navigate the others' systems. This is the reported experience of Iowa providers. HIV providers feel that substance abuse and mental health professionals do not understand the complex issues their clients face. Likewise, they are often overwhelmed by the complexity of co-morbidities. In addition, it is sometimes difficult to identify the providers of mental health and substance abuse services in a given community.

Although there are some areas in the state with cross-training, education, and mechanisms for collaboration in place, no consistent, state-level structure exists for all providers. For example, statewide substance abuse professional licensure standards[50] are vague, and lack clear language regarding the roles of substance abuse professionals who work with persons living with HIV. Consequently, licensed substance abuse professionals may not know how to integrate substance abuse treatment services via collaboration with other providers, how to work with HIV care teams to improve client outcomes, or even how best to counsel clients with HIV/AIDS and substance abuse issues. The Center for Substance Abuse Treatment, a part of the Substance Abuse and Mental Health Services Administration (SAMHSA), has developed a protocol for substance abuse treatment of persons with HIV/AIDS as part of their Treatment Improvement Protocols series, but how widely used this is in Iowa is not known.

Mental health and substance abuse service providers continue to experience minimal increases in federal funding. The challenging economic climate and the unknown of healthcare reform necessitate a need for tight fiscal management. Substance abuse and mental health block grants are requiring a consolidation of resources and thus increasing the requirements for collaboration between mental health and substance abuse systems. Though this creates challenges in implementation, it is an exciting development that will ultimately benefit the citizens of Iowa, including those living with HIV. It creates an optimistic framework for service delivery for those with the highest needs.

[50] Iowa Code 643, Chapter 3, 3.21(11).

Department of Corrections and County Jails

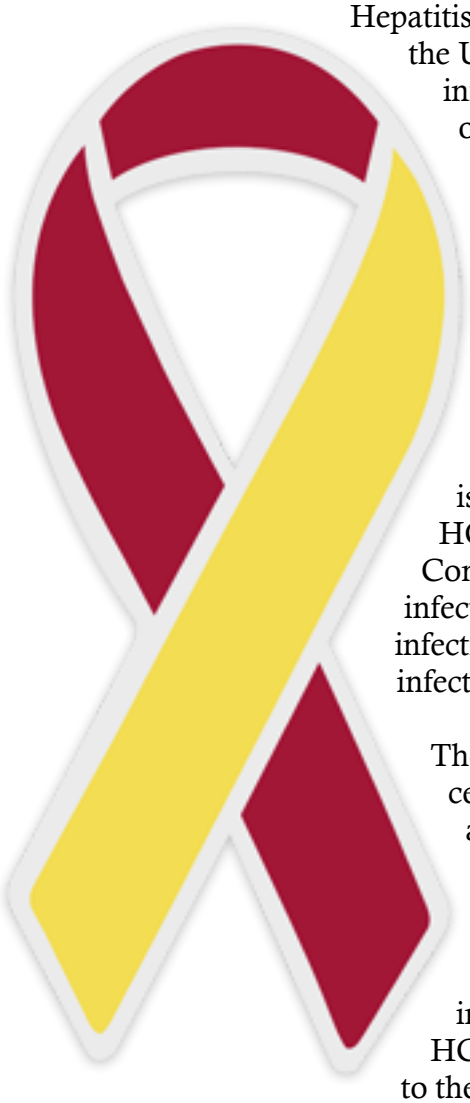
In FY 2011, Iowa served 13,461 offenders in the prison system and 56,893 offenders in community-based correctional settings.[51] Iowa's correctional facilities provide both opportunities and challenges to ensuring care for incarcerated PLWHA. Incarceration provides a unique opportunity to identify and address HIV infection, with direct access to testing and healthcare. All inmates in the state prison system are tested for HIV upon entry. Until the end of 2011, Iowa's prison inmates were provided basic education through the *Reach One – Teach One* program, which served thousands of inmates each year. This program has been discontinued due to the reduction of funding to Iowa's HIV prevention program from CDC. Inmates continue to receive HIV and hepatitis C virus testing when they enter the state's prison system, with an additional HIV test provided a year later.

Significant numbers of PLWHA have some history of incarceration. In the 2011 Consumer Needs Assessment, 44% of respondents said they have been in prison at some time in their lives. This is an increase from 2008 (34%) and 2005 (28%). With such a high percentage of incarceration among PLWHA, collaboration with the Iowa Department of Corrections and county jails remains a priority. The collaborative process could be improved by becoming more formalized, particularly in relation to discharge planning and re-entry.

Integration with STDs and Hepatitis C

Recent trends in STD and hepatitis C rates among PLWHA and key groups at risk for HIV indicate the need for increased prevention programming for HIV-positive persons and for better collaboration with local public health and STD prevention providers. The incidence of reportable STDs in Iowa has been increasing for many years. For example, chlamydia cases have nearly doubled since 2000 and gonorrhea cases have increased by 42%. While the majority of these cases are among persons 15 to 24 years of age, 50% of syphilis cases occurred among persons 30 to 55 years of age in 2011. In addition, the majority of syphilis cases are among men, with cases of early syphilis for men outnumbering those of women 3 to 1 in 2011. Among these men, the majority are men who have sex with men, with the proportion of MSM rising. Furthermore, all of the reportable STDs are disproportionately diagnosed among black, non-Hispanic and Hispanic populations. STDs and hepatitis C can complicate HIV treatment and care and can facilitate the spread of HIV to other persons. According to the 2011 Consumer Needs Assessment, 8% of respondents reported co-infection with one or more STDs.

[51] Iowa Department of Corrections. Quick Facts; 2012 April.



Hepatitis C virus is the most common chronic, blood-borne viral infection in the United States. It is estimated that 1.8% of the U.S. population is infected, including approximately 52,000 Iowans. Many are unaware of their infections. The most common route of transmission is injection drug use; other risk factors include receiving blood transfusions or organ transplants prior to mid-1992, treatment with blood products before 1987, and long-term kidney dialysis. Both HIV and HCV can be transmitted through blood-to-blood contact. Iowans living with HIV who were infected through injection drug use or blood transfusion may also be infected with HCV. The 2011 CNA asked Iowans living with HIV if they were co-infected with HCV. Eleven percent of respondents reported co-infection. However, the co-infection for Iowa's total HIV-infected population is unknown because this is not asked as part of HIV surveillance, and HCV surveillance is incomplete in Iowa. The Centers for Disease Control and Prevention estimate that approximately one quarter of HIV-infected persons in the United States are also infected with HCV. Co-infection with HIV and HCV is very common (50% to 90%) among HIV-infected injection drug users (IDUs).

The effects of HCV co-infection on HIV disease progression are less certain. A majority of studies suggests that hepatitis C does not accelerate HIV disease progression.[52] However, there are reports of HCV becoming a major cause of death in persons with well-controlled HIV infection.[53] Because co-infected patients are living longer on HAART, more studies are needed to determine how HCV infection influences the long-term natural history of HIV infection and, conversely, how HIV influences the progression of HCV disease. In 2007, medications to treat HCV infection were added to the ADAP formulary. HCV testing and immunizations for hepatitis B and C have been offered at many IDPH-supported CTR sites since 2002.

Prevention Counseling Delivered by Care Providers

Although physicians and nurses specializing in HIV care are familiar with HIV prevention, they find it difficult to deliver appropriate prevention messages in the time allotted for each patient. At the same time, Ryan White case managers have had varying levels of success with integrating prevention counseling into the services they provide. In some cases, case managers found it difficult for clients to prioritize prevention when competing needs are often of an emergency nature. The comfort level in discussing prevention issues also varies between clients, medical providers, and case managers. Additional training, specially tailored interventions that can be easily integrated into clinic/work flows, and increased collaboration is necessary to support the integration of prevention counseling in medical care.

[52] Hepatitis C Support Project, Fact Sheet: HIV/HCV Coinfection, January 2007

[53] Arthur Kim, et al. Impaired Hepatitis C Virus-Specific T Cell Responses and Recurrent Hepatitis C Virus in HIV Coinfection. PloS Medicine **Vol. 3, No. 12, e492 doi:10.1371/journal.pmed.0030492.**

Cultural Competency

Both oral (interpretation) and written (translation) language issues are becoming more common for testing, prevention, and care. Over 200 PLWHA (15% of all PLWHA in Iowa) are foreign-born, but this varies greatly throughout the state. Africa and Central America (including Mexico) are the most common places of origin for foreign-born HIV-positive persons in Iowa. It is sometimes difficult to compete with higher-paying corporations for competent bilingual staff. Staff members who are fluent in speaking are not always competent or comfortable with written translation. However, one provider noted recent improvements in providing services for Spanish speakers.

Iowa is home to an increasing number of HIV-positive Africans who speak a variety of languages, some tribal or geographical, and not widely spoken in the U.S. Very few written materials are available in African languages. Limited resources often make it difficult to provide quality service to these clients.

Literacy is an issue among Central American and African clients, especially females. Even if written information is available in their primary languages, clients are often unable to access the information. Staff must spend more time providing and reviewing information orally. The high volume of clients, combined with limited staff and interpreters, cause a definite gap.

As client diversity increases, so does the number of cultural systems providers must navigate to serve them. Cultural systems impact risk reduction, gender roles, and healthcare beliefs. It is nearly impossible for staff to be culturally competent in every aspect of care. Case managers need ongoing training and resources for translation, consultation, problem solving, and understanding the complexities of the cultures they serve.

Continuous Quality Improvement

Quality is the degree to which health or social services meet or exceed established professional standards and user expectations. Quality assurance involves identifying successes and challenges in service delivery, and designing continuous quality improvement activities to overcome them. Quality management supports the development of higher quality care for people living with HIV disease, improves the performance of local HIV service delivery networks and providers, and helps them function as a system.

The Iowa Department of Public Health has made quality management and assurance and program evaluation a high priority department-wide. Quality Management (QM) and evaluation activities are necessary in helping to determine whether services are achieving the intended outcomes of improved access to prevention and care, including reduced HIV infections, increased serostatus knowledge, better retention in care, better adherence to HIV medical regimens, and reduced HIV transmissions.

Of course, there are other poignant reasons to have a strong quality management program. As the number of

new diagnoses increases, and as PLWHA live longer, HIV clinic and agency caseloads are increasing. Quality management data can help to ensure that the quality of services do not decrease in the face of increasing workloads. In addition, as HIV becomes increasingly concentrated in racial and ethnic minorities and the poor, cultural competency among prevention and care providers and relevancy of services must be monitored to ensure optimal access. People at risk for HIV and newly infected individuals are also more likely than ever to have low incomes[54] and to have particularly complex and extensive needs. Similarly, as PLWHA age, their needs are becoming more complex and extensive. The increased demand for HIV-related support services will create the need to deliver those services with greater efficiency. A well-designed and implemented QM program can help achieve that goal.

Reporting
With the implementation of a new Comprehensive HIV Plan and an integrated plan development process, an opportunity to review and update practices for monitoring and evaluating progress in achieving statewide goals and objectives is presented. Currently, annual program reports are provided to the CPG with the opportunity to ask questions and request additional information. Iowa's quality management program may benefit from a more formalized approach to progress reporting based on periodic updates to implementation plans that are based on the plan.

Statewide Quality Management Plan
The Plan Development Committee also established a goal to form a statewide quality management plan. Although various quality initiatives exist throughout the state, there is no one centralized plan. This plan will be designed to cross all aspects of HIV prevention and care and will be used to set quality improvement goals, to measure progress, and to report outcomes.

CDC's Expectation for Planning, Monitoring and Evaluation, and Quality Assurance (QA)
CDC requires that funded state health departments implement quality assurance measures to support components and activities being implemented and to improve program quality and accountability. Development and implementation of QA mechanisms and measures ensure that:

- Services are provided in a technically competent manner and are consistent with current CDC guidelines and recommendations;
- Services are culturally and linguistically appropriate and staff is trained accordingly;
- Staff has appropriate training for their respective roles;
- Positive test results are reported to the appropriate local or state surveillance and Partner Services programs, in accordance with applicable laws and regulations;
- Appropriate laboratory QA procedures for HIV testing are in place; and
- QA policies and procedures are available and accessible to all staff working in this program and with CDC.

To meet CDC's requirements, IDPH must also work with the CPG to:

- Monitor the HIV/AIDS epidemic within the jurisdiction for program planning, resource allocation and monitoring and evaluation purposes; and

[54] Karon, et al. "HIV in the United States at the Turn of the Century: An Epidemic in Transition," *AJPH,* Vol. 91, No. 7, 2001.

- Develop and submit to CDC a detailed comprehensive program plan that includes a monitoring and evaluation (M&E) and quality assurance (QA) plan, collectively referred to as the Comprehensive Program Plan.

Overview of Prevention Quality Management in Iowa
The IDPH prevention program has invested over the years in program evaluation and monitoring. The results have helped better target HIV prevention services and testing throughout the state. An HIV prevention program evaluator is supported to monitor the implementation and effectiveness of prevention services and to report trends, opportunities, and barriers to CPG, providers, the community, and the CDC. This information is used in the evaluation of interventions, the selection of priority populations for testing and prevention, and the identification of quality improvement activities.

IDPH contracts with Luther Consulting, LLC, to utilize their web-based system, EvaluationWeb, for data collection and analysis. EvaluationWeb is designed to meet CDC program requirements and Iowa's specific evaluation and data needs, and has continued to adapt throughout multiple program changes. The system now has improved access to reports, allowing for better data interpretation and management of quality performance. This is true for the state (to evaluate contractor performance) and local level (for contractors to use internally for ongoing quality management).

IDPH initiated monthly data quality assurance (DQA) checks for both CTR and HE/RR interventions. The purpose of the DQA checks is to ensure that data are submitted accurately and completely. In addition, the monthly DQA provides an opportunity to track progress toward goals and to problem solve as soon as challenges arise. Counseling, Testing, and Referral DQA compares the month's data set from EvaluationWeb to a report generated by the State Hygienic Laboratory, which processes the HIV and HCV tests, and the monthly HIV rapid testing quality assurance report submitted by contracted agencies. Findings are summarized in a one-page document, and include an opportunity for agencies to address any potential discrepancies.

Health Education/Risk Reduction DQA compiles two different reports from EvaluationWeb, including the number of clients who enrolled and how many completed all expected sessions. The report also tracks demographics and risk behaviors of participants and addresses whether these match the interventions' intended audiences. All DQA reports are sent to agencies to compare to their records.

Federal Expectations and Opportunities for Quality Improvement – Ryan White
A major focus of the HRSA's Ryan White HIV/AIDS Program is not only to eliminate barriers to accessing care, but also to improve the quality of care that clients receive. Legislative requirements found in the Ryan White HIV/AIDS Treatment Modernization Act of 2006 direct grantees to develop, implement, and monitor clinical quality management programs to ensure that:

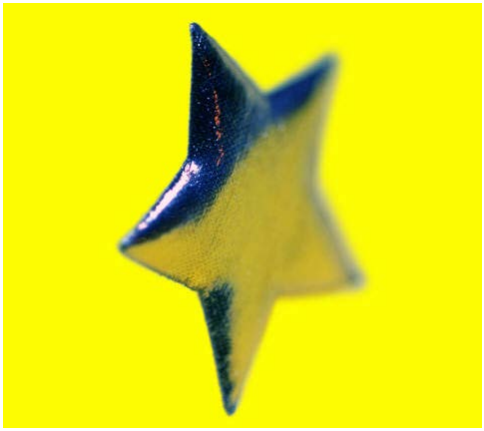
- Service providers adhere to established HIV clinical practices;
- Quality improvement strategies include support services that help people receive appropriate HIV healthcare (e.g., transportation assistance, case management); and

- Demographic, clinical, and healthcare utilization information is used to monitor trends in the spectrum of HIV-related illnesses and the local epidemic.

The purpose of the quality management program is to ensure that:

1. Services adhere to established HIV treatment guidelines;
2. Health-related support services enhance access to care and adherence to HIV medical regimens; and
3. Demographic, clinical, and healthcare service utilization information is used to monitor HIV-related illnesses and epidemic trends.[55]

Overview of Ryan White Quality Management in Iowa



The Ryan White program has been integral in championing a system-wide culture of quality. The Ryan White program manager is an IDPH performance management champion, and is helping to coordinate a division-wide standardization of contract monitoring. The Ryan White program is participating in a department-wide pilot project as a step in the Department's development of a robust performance management program. The project has resulted in an expansion of performance measures directly tied to program outcomes. The expansion will dovetail nicely with other quality management goals and initiatives such as Healthy Iowans, the Iowa HIV Comprehensive Plan, the Iowa All Grantees Quality Management Plan, and the Part B Quality Management Plan. The new indicators will be detailed in the 2013 Iowa All Grantees and Part B Quality Management Plans.

To ensure quality health and supportive care to Iowans living with HIV, Iowa needs to continue to implement and improve quality management programs. Special attention should be paid to revising case management standards to reflect a more medical model, to placing a stronger focus on promoting and evaluating client self-management and cultural competence of providers, and to improving data collection and measures of quality.

In addition, the Ryan White Part B program and two Ryan White Part C programs are participating in the National Quality Center's in+care campaign. The goal of the in+care campaign is to bring patients back to care and keep others from falling out of care. The national initiative is a no-cost, voluntary quality improvement effort focused on retention. It is anticipated that this will allow Iowa to focus efforts and promote coordination between Part B service providers and Part C clinics in Iowa to a greater capacity.

Case Management Program

Iowa has a strong history of providing high-quality case management services to Iowans living with HIV. Part B case management standards were developed and implemented in April 2004. Standardized forms and procedures were subsequently developed. Implementation of the case

[55] HRSA 2002 Ryan White CARE Act Manual

management standards and standardized forms was essential in developing the Part B quality management program. They also provided a framework to launch a comprehensive case management certification program in April 2012.

To improve uniformity and consistency of case management service delivery in Iowa, the Ryan White Part B Program has contracted with Diverse Management Solutions, LLC, to deliver an HIV medical case management certificate program that consists of eleven online trainings and two full-day workshops. The certificate curriculum is based on input from AIDS service organizations, the Denver Transitional Grant Area, the Boston College Graduate School of Social Work, and others. Its online trainings modules include Motivational Interviewing, Service Planning and Monitoring, Approaches to Difficult Situations, Harm Reduction, Helper as a Person, HIPAA, Mandatory Reporting, Multiculturalism, Stages of Change, and Therapeutic Communication. The in-person training includes sessions on Best Practices of Case Management, Positioning Clients to Succeed, Motivational Interviewing, and Thrive: Being the Best Case Manager Possible. In addition to these overarching topics, Iowa focused sessions such as training on CAREWare, Iowa's HIV transmission law, Iowa -specific quality management and Iowa planning procedures.

CAREWare

The Ryan White Part B Program implemented the statewide deployment of CAREWare in September 2008. A central server is used to house data from all Part B providers, including the ADAP and one Part C provider. Two other Part C clinics in Iowa utilize CAREWare to maintain their client-level data. Utilization of the current version of CAREWare will ensure that all required client-level data elements will be collected by providers and reported to HRSA.

Furthermore, the "real time" nature of the networked system allows the Ryan White Part B Program to monitor specific indicators more closely (e.g., number of clients without medical insurance), instead of waiting several months until the provider is required to submit a report. Iowa is one of the first states to use the ADAP module in CAREWare, and there is great potential for measuring and improving quality through this mechanism. CAREWare allows the sharing of information between agencies, thereby improving referral times, the tracking of clients, and the tracking of quality indicators.

Summary Analysis of Gaps and Future Directions for Iowa

Much remains unknown about the future of federally funded HIV services. Health reform offers a combination of welcomed optimism for increased access to health services and an equal level of concern about implementation and whether Iowans living with HIV will have unfettered access to these new resources. Medicaid expansion, health insurance exchanges, and medical homes will require a new learning curve and many clients will require, or at least benefit from, advocacy and navigation of these services. Primary prevention services may shift from safety net providers like local public health clinics to primary care providers that are directed by managed care organizations. In addition, care providers will have a lot to learn about the new healthcare system and may even require great shifts in organizational structure whether applying to become a federally qualified health center or gaining the capacity to bill for services.

What is Ahead for Iowa?
Iowa has experienced a relatively low incidence of HIV/AIDS, and has had a good distribution of programs for residents affected by the disease. A reduction in prevention funding, and the unknown future of other HIV resources, however, introduce a significant threat to Iowa's current system of prevention and care.

Even without budget cuts, significant obstacles and gaps in services for those living with and affected by HIV/AIDS continue. Affected residents wanting to become and stay healthy are challenged by structural barriers, stigma, economic hardship, long trips to medical providers, and gaps in service provision. An estimated 20% or more of people living with HIV are unaware, and for numerous reasons, do not access testing services. In addition, 30% of Iowa residents who know they are HIV positive are not receiving regular medical care for their HIV disease.

The following section outlines goals and activities for the next three years. An increased focus will be placed on finding HIV-positive persons early and linking and retaining them in care. Behavioral prevention interventions with HIV-negative individuals will no longer be the primary prevention tool that is used in the state of Iowa. Treatment will be our foremost prevention intervention and any other prevention efforts will be very narrowly targeted (e.g., testing, condom distribution) and/or funded by alternate sources. Policy and systems change efforts will also be a priority focus in order to remove barriers that limit the efficient use of resources.